





















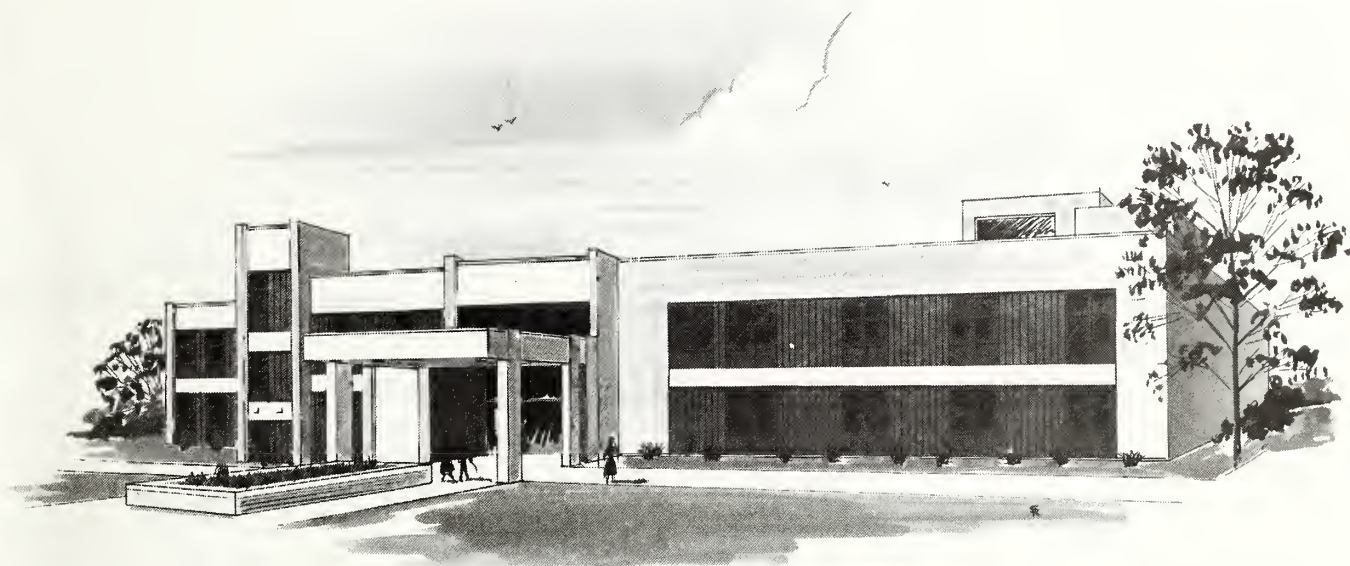




Special Message  
Inside



# NAT-CENT NEWS



Published 3 times a year by:

Helen Keller National Center for Deaf-Blind Youths and Adults

111 Middle Neck Rd.

Sands Point, N.Y. 11050

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Operated by Helen Keller Services for the Blind

**EDITOR — ROBERT J. SMITHDAS, L.H.D., Litt. D., L.H.D.**

Editorial Assistant — Allison Burrows

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January, 1991

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## **NAT-CENT NEWS**

Dear Subscriber:

Please take notice that  
this issue contains a  
special notice on the last  
page. Thank you.

- Editor



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## **EDITORIAL IN PRAISE OF CITIES**

By Robert J. Smithdas, LHD, Litt.D., LHD

After many years of living in a variety of environments, I have come to the final conclusion that the best place for a severely disabled person to live is in a city. Cities provide a wealth of accessible services and assets that can add a tremendous impact to the goal of "independent living."

Deaf-blind people need to live in locations where there is readily available transportation, accessible shopping and services, and where there is a good flow of pedestrian traffic with people who can assist them in crossing streets or finding specific places that are needed. Being able to travel freely, using buses, subways and other facilities promotes a sense of confidence and pride.

Most American towns lack adequate transportation for disabled people. Their populations are usually car-oriented and there is usually little pedestrian traffic in residential neighborhoods because the residents prefer to

use their vehicles to drive a few blocks to local shopping and services. Finding a dependable volunteer who will provide assistance when needed is a problem because volunteer groups are usually absent.

Independence is a relative thing. All of us, in varying degrees, are dependent upon others for a satisfying life and self-fulfillment. We need to recognize that a disability means limitations and that the more severe it is, the more limitations it imposes, no matter how ingenious and resourceful the disabled person may be.

Carl Sandburg, the poet, characterized Chicago as a rough-and-ready city, the "city with the big shoulders." Most American cities are similar today - unpredictable, rough and boisterous.

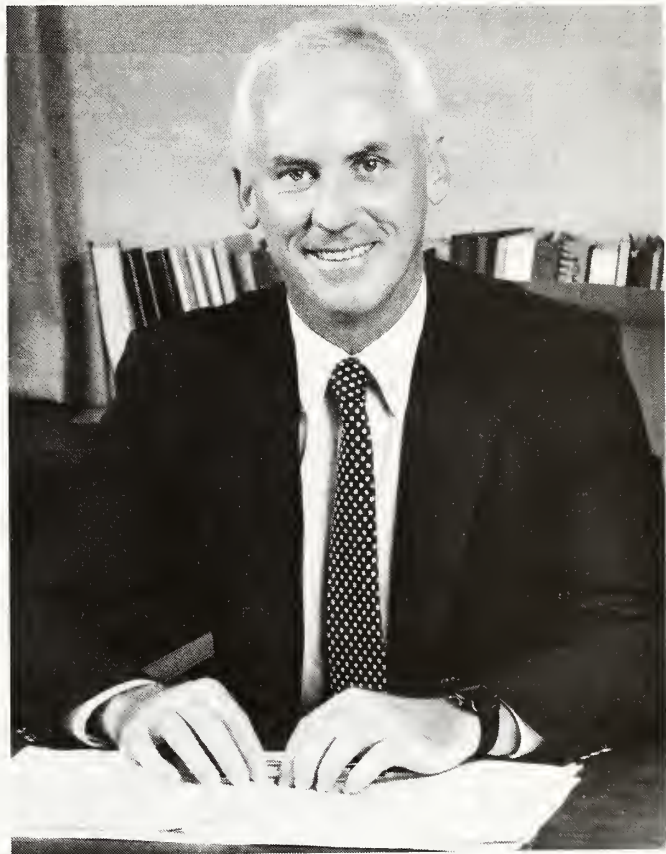
But my choice would be to live in a city where the streets are crowded with pedestrians who can assist in crossing streets; where buses and trains run regularly on the half-hour; and where there is easy access to the corner drugstore, the Italian restaurant,



and the local dry-cleaner or laundry. It means easier living in an enabling environment.

## **NEW DIRECTOR APPOINTED AT HKNC**

J o s e p h J . McNulty has been named director of the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC), it was announced by Fred McPhilliamy, chairman of the Board of Trustees of Helen Keller



Services for the Blind (HKSB), which operates the Center. Mr. McNulty, previously assistant director of the Helen Keller National Center, assumed his new position on November 1, 1990.

"Mr. McNulty's long-time experience and

accumulation of expertise in the field of deaf-blindness and with the Helen Keller National Center is outstanding," said McPhilliamy. "We are confident that his stellar qualifications will ensure a continuing leadership role for the Center and all people who are deaf-blind."

Beginning as a mobility instructor at HKSB (formerly The Industrial Home for the Blind) in 1976, McNulty taught orientation and mobility skills to adult clients and physical education and mobility training to children at HKSB's Summer Day Camp. For three years he served as an orientation and mobility instructor at HKNC and was then appointed residence director. In 1985 he was named national coordinator of affiliated services and was responsible for the development and monitoring of some 30 multi-service public and private agencies which, in turn, expanded or improved services for individuals who are deaf-blind nationwide. Two years later, McNulty was appointed an assistant director with responsibilities for

HKNC's national network of field services, including 10 regional offices, affiliated agencies, a National Training Team, and job placement specialists. During his tenure, a new program was established which addressed the emerging needs of older adults with vision and hearing loss and provided support and training services for this population.

"The immediate challenge for HKNC is to work cooperatively with consumers, parents and professionals to ensure access to and inclusion within existing services and new initiatives for our special population," noted the new director. "Our goal is constant; that is, expanded opportunities for people who are deaf-blind to live and work in the community."

Mr. McNulty earned his Bachelor of Science degree at Niagara University in Lewiston, NY, and his Master's degree in Adapted Physical Education from Adelphi University in Garden City, NY.

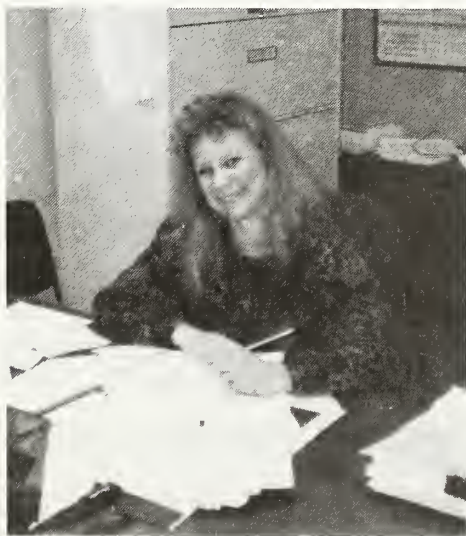


## CHANGES AT THE CENTER

Dennis P. Brady, who for the past few years has served as HKNC assistant director in charge of direct services, responsible for overall training services and the residential program at the Center,



has assumed responsibility for HKNC field services. Mr. Brady will be in charge of the Center's ten regional offices, the National Training Team, and the Center's program for affiliated agencies.



Susan Ruzenski, a long-time HKNC staff member, has replaced Mr. Brady as director of professional services. Ms. Ruzenski has served in various areas of the Center's ongoing program, including

supervisor of Daily Living Skills and supervisor of the Communication Learning Center. She brings a unique background of hands-on experience and expertise to her new position.

## **PROFESSIONAL NURSING SERVICES** **AT HKNC**

By Normadeane Armstrong, R.N. B.S.N.

The nursing role at HKNC is a unique one. Besides providing general health care for each client, nurses are involved with health education (previously known as health and hygiene). Many people acquire knowledge of nutrition, disease and sexuality through television, radio, newspapers or society in general. Individuals who are deaf-blind may not have access to this media due to their dual handicap. To care for this type of population, nurses must possess a strong background in medical-surgical nursing. This is necessary so they can detect the early signs of disease and educate the client in



prevention as well as treatment.

Some of the areas covered in health education are human sexuality, medication administration, preventive medicine and diabetes.

In the area of human sexuality, our goal is to assist the client in gaining a positive perspective of his/her own sexuality. We provide the client with a solid, factual frame of reference by which he/she can handle any sexual encounter. Some of the topics discussed are anatomy and physiology, conception, sexually transmitted diseases, contraception and legal issues such as rape and prostitution. We utilize various aids and devices to assist in the learning process. These include the Jim Jackson gender dolls and reproductive models as well as various films that are available in closed caption and sign language.

In the area of medication education, our goal is to assist the client in becoming more independent with medication administration. The degree of independence varies with each



client. Some clients use a device called a medication box where each compartment is brailled with the appropriate day of the week. Other clients that can function beyond this capacity, obtain experience with consumerism. The clients shop for generic medication as well as become acquainted with the pharmacist. In turn, the client learns to access the pharmacy's services in order to answer questions concerning medications.

In the area of preventive medicine, our goal is to assist the client in gaining a positive perspective of his/her own body. We discuss the importance of yearly physical and dental exams, as well as introduce the necessity of gynecology exams. Clients are taught self-breast and testicular examination as well as other measures to prevent illness. Again we utilize various models and films to accentuate the lesson taught. Hypertension, heart disease and nutrition are also discussed.

In the area of diabetic education, our goal is to assist the client in becoming more independent with diabetic care. It is a

difficult task to change written and verbal information about diabetes into a gestural form. However, there is great satisfaction obtained by allowing the clients more independence through teaching them to administer their own insulin. In addition to classroom education, diabetics are also taken into the community to learn about various available products. These may include sugar-free, over-the-counter medications and sugar free items found in the supermarket.

The Medical Department is currently in the process of implementing two new programs to further the client's health related independence. The first program is the Socialization and Sexuality Group. Once the client finishes education in human sexuality he/she is placed in a group run by the clinical social worker and the Nursing Department. Issues such as dating, relationships, sex and marriage are discussed. The other program combines health education with the Independent Living Experiences. Here clients are instructed in assembling their own First

Aid Kit and purchasing their own supply of over-the counter medications. They are also instructed in procedures to follow in case of a medical emergency.

There are many advantages of being a nurse at HKNC. There is great personal satisfaction obtained by assisting the individual in gaining independence as well as watching the clients become more knowledgeable about their bodies. Because of the uniqueness of HKNC, and the type of nursing care involved, we are proud of the services we provide.

**CHERYL BROWN FINDS STRENGTH,  
INDEPENDENCE DESPITE ADVERSITY**

Reprinted with permission from the  
Monmouth College News, Monmouth, NJ

Cheryl Renee Brown was born with a hearing loss, began to have vision problems at age 13, and may lose all of her vision due to a hereditary condition known as Usher's syndrome. She's spunky and articulate and is



the first person to tell you, "I'm hearing impaired and my vision may deteriorate. I don't know what will happen, but I'm confident and prepared for what's down the road."

Raised in East Orange, where her parents and grandparents still live, she returned to her apartment there after completing 12 months of special rehabilitation training at the Helen Keller National Center. She now lives independently and has begun the search for a part-time job.

Ms. Brown, who attended East Orange Junior and Senior High Schools, spent her grammar school years in a special class at the Franklin School in Newark.

She received a bachelor's degree in Business Administration from Monmouth.

"The next four years I tried to find some direction for my life, so I settled down in Goodwill Industries of New Jersey to try to develop some skills for employment," said Ms. Brown. "Then I experienced more vision problems and my state counselor

recommended special training at the Helen Keller National Center. There I learned braille, communication skills like American Sign Language and the manual alphabet, and even safe cooking methods."

Ms. Brown had an opportunity to work in a clerical job on the Center's campus, and then had a "real life" work experience in the Nassau County Social Security Office. She participated in a 10-minute video called "Partners in Success," which focuses on employing people who are deaf and blind.

At the Center, Ms. Brown became computer literate, learned about the keyboard and special software called Zoom-Tech or Vista, which outputs information in large print. She also became familiar with the Word Perfect and Friendly Writer programs.

Ms. Brown also represented her fellow clients and the Center on a steering committee that organized and planned monthly town hall meetings.

"I've learned a great deal from the staff at HKNC," said Ms. Brown. "I've gained self-

confidence and discovered new leadership abilities. I feel more independent and am motivated to look ahead and to lead a positive life. I have also developed more skills so that I can adjust to the work place. I may even go on for further education. But no matter what happens to my vision and hearing, I can still go on."

### **FROM THE CITY OF BROTHERLY LOVE**

Liberty Center for Independent Living provides services to persons with disabilities in the Philadelphia region. Formerly the Center for Independent Living at Associated Services for the Blind, located at 919 Walnut Street in Philadelphia, it is a consumer-controlled, community-based center that provides a variety of services for disabled people in a five-county area.

Among the services provided by the Center are peer counseling; skills training; advocacy; information and referral;



recreational activities; stress management and assertiveness training; and, technical assistance and training. Many other services are available.

As of October 1, 1990, Liberty Center opened a new and expanded program for deaf-blind and hearing/vision impaired consumers. Rod Visser, who is deaf and visually-impaired himself, was hired as coordinator of the program.

Rod Visser earned his Bachelor of Arts degree at Gallaudet University in 1983, majoring in psychology. He received a Master of Science degree in Deaf-Blindness from Western Maryland College in 1987.

Rod has worked in the field of deaf-blindness since 1983. Prior to joining Liberty Center for Independent Living, he worked for three years at the Overbrook School for the Blind as a unit supervisor and direct care counselor in the school's deaf-blind program. Rod is enthusiastic and excited to be at Liberty Center, and eager to develop a program to meet consumers' needs.



Mrs. Ann Siccinotti, who is also hearing and visually impaired, will assist Mr. Visser as a basic skills trainer and peer counselor. Ann is an experienced teacher who earned her Master of Education at Gallaudet University in 1963. She joined Liberty Center after working twelve years at the Woods School in Langhorne, Pennsylvania. Her experience in special education will be beneficial in providing assistance and counseling to consumers.

**CLIENT VIEWPOINT: MY TRAINING  
AT THE CENTER**

By Lance Kamaka  
(Client from Hawaii)

First of all, I want to state that since I came to the Helen Keller National Center for training, I have been learning many things. There have been four major areas of training that have been very beneficial for me.

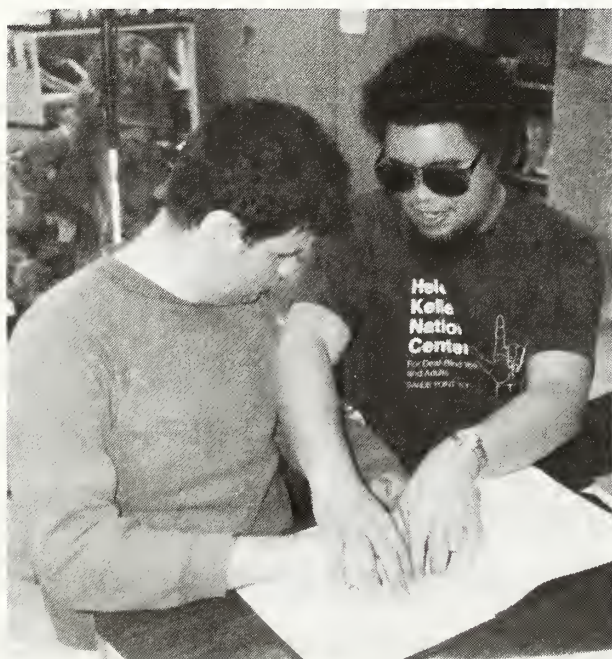
First, there is the area of communication. If anyone asked me what skills I have

improved in the most, I would have to say that, without a doubt, it is the ability to communicate with other deaf-blind people. Prior to joining the Center's training program, I had learned the one-hand manual alphabet for the deaf. But the only person I had used this method of fingerspelling with was my wife, and it had been very slow compared to the speed I have developed now. I also learned a bit of sign language in addition to improving my fingerspelling skills. Two signs at I learned come in very handy: "slow down" and "repeat!"

A second area in my training experience that has become important is home management. I've learned to prepare a lot of my meals by using the microwave oven and the toaster oven. I was involved in the Independent Living Experience (ILE), where I practiced taking care of an apartment and all the chores that come with living in one's own home. I found ILE one of the most challenging areas of my training, and one that I may certainly use in the future.



For a while now I have been working in the Communication Learning Center, where I am being given experience as a teacher's aide. I enjoy it very much because it gives me an opportunity to teach and to do what I have been doing since I was in grade school - working with braille. I was assigned two clients with whom I work twice each week. It is a very rewarding experience to watch them progress in their braille skills, reading and writing braille. Not only do I teach, but I am learning a lot myself.



Lance assists client, Adam Gray, with his braille as part of the teacher's aide experience.

Sometimes I'm asked questions about the rules of braille, which I have always taken for granted. To me, braille has always seemed automatic for reading and writing - I never thought about its rules. It helps me when I

need to consult with my supervisor or look the rules up on my braille transcriber's manual.

Both clients I work with are hearing impaired. Because they can both speak, communication with them is not a great problem. They also have a good general knowledge of the braille system and how it works, and that makes my work easier. But I realize that it would really be a challenge to teach someone braille "from scratch!"

I feel that more emphasis should be placed on the use of braille for reading and writing. I know that lately there has been a misconception by educators concerning people who are losing their vision. They have tended to think that whatever residual sight remains should be used to read and write, which means not using braille. I firmly believe that braille should be taught to those losing their sight and that those wishing to learn it should be encouraged.

I have been using this teaching experience as part of my work experience at the Center.



Hopefully, when I go back home to Hawaii I'll be able to get a job working with people who want to learn braille. I want to extend my appreciation to all the wonderful staff at the Center who have provided me with these experiences and the training I have received. It's all been very worthwhile and rewarding!

### COMPUTERS AND THINGS

by Ray Pitts. Reprinted with permission  
from THE PORT WASHINGTON NEWS,  
Port Washington, NY

A corner room on the second floor of the Helen Keller National Center is a bit cool even on the warmest days. Whether by accident or design, it's a good thing because lined up along the walls of the room are computer terminals and a wide variety of other electronic devices. When they're all on and in use they can generate some heat.

They are also generating some excitement among a select few who are pioneering in learning new communications and vocational

skills in this "room of the future." The electronic aids, communication devices, computers and adaptive equipment found in this newest addition to the Communications Learning Center are the result of the recommendations of a special task force.

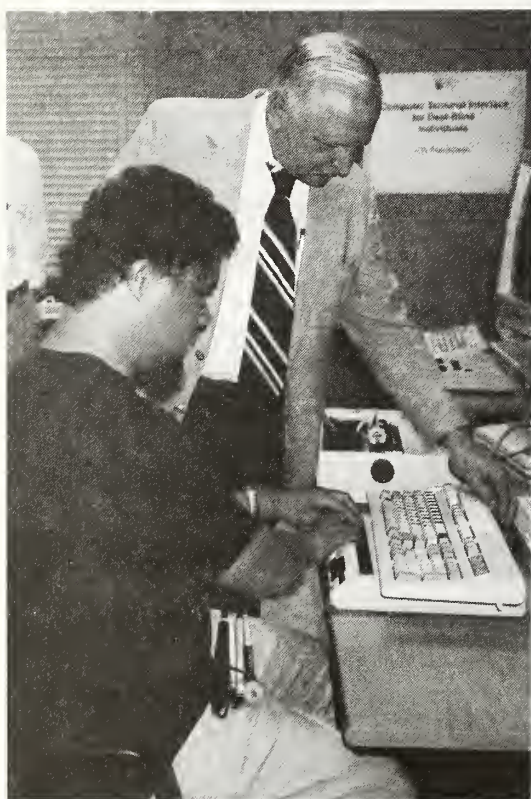
Mr. Tom Mierswa, retired IBMer, said the task force recognized the rapidly growing value of technology in aiding people who are deaf-blind. "We recommended," he said, "that the Center enhance its leadership position in developing, finding and using that technology." The new facility is the early result of those recommendations.

In May of 1990, Mr. Carl Franckowski, former staff member, started teaching clients how to use computers and computer-related electronic devices. "It fits right in with the rehabilitation training we provide for our clients with varying degrees of hearing and vision loss," he said. "We use this latest technology to help individuals learn word processing using large print software programs, access and create braille output to



read - to name just a few of the things we are doing here."

Imagine the thrill of learning to type and knowing you have not made a mistake even if you can't see the keys or the computer screen. Imagine being able to have what you have written typed out, automatically in letters or in braille for someone else, sighted or not, to read.



Client, Lance Kamaka, demonstrates the Navigator to Robert Smithdas, assistant director.

Imagine, even though deaf-blind, being able to turn on the television set and "see" and "hear" through your fingers the action in a major sporting event or the breaking news in a major story.

Imagine being deaf-blind, but able to develop a program on your computer, transmit messages to other computer users by way of your computer keyboard, "read" what's on computer



diskettes and then being able to use that diskette in your computer to perform some task without someone there to help.

These things are practical miracles to people who are deaf-blind. Now, many individuals who are deaf-blind can do all of these things and more - thanks to the advances in technology and the skills of the people and companies who fund, develop and manufacture these devices.

The hardware and computer software available cannot be adequately catalogued here. To satisfy a small curiosity, and to whet your appetite for more information, a few names associated with the equipment now in use are: IBM, Commodore, Science Applications International Corporation (SAIC), Braille TeleCaption System TeleBraille, TeleSensory Inc., and others.

For those who need to know more about this equipment, who makes it, how it works and who can be trained to use it at the Center, write to Barbara Hausman, Helen Keller National Center, 111 Middle Neck

Road, Sands Point, NY 11050.

**INTRODUCING. . .VIBRA-CALL**

by George J. Elwell, President, Silent Call Corporation

We are proud to announce the release of our latest system "Vibra-Call" for deaf-blind people. Never again will a deaf-blind person be expected to feel a fan blow on them to let them know of events taking place. Never again will a deaf-blind person have to adjust sound activated products to monitor their area. Never again will a deaf-blind person be expected to fight with the products just to change a battery.

Vibra-Call, the new personal alert system for deaf-blind people is an advanced wireless system that monitors household devices such as the phone, smoke detector, doorbell or a baby crying.

Worn as a pager close to the body, the receiver unit vibrates when signaled by one of the transmitters. The deaf-blind person then

pushes each of four buttons in a learned order. Only the button activated will cause the receiver to vibrate a second time, thus alerting the person to the correct transmitter activated.

The Vibra-Call system is dependable every time because it monitors only its own electronic signals. Other systems based on sound monitors will invariably send off false signals.

### The System Components

Vibra-Call Receiver #4001-1: The pager-like receiver is a light-weight unit worn close to the body so the vibration can easily be felt. A built-in clip easily attaches to a belt or waist of a skirt. The unit will also fit in either a shirt or pant pocket. The Vibra-Call Receiver unit operates on a rechargeable 9-volt battery.

Smoke Detector #1008-1: Completely self-contained, the Smoke Detector simply mounts to the ceiling or wall with velcro and



is easily removed for continued use while on vacation. The transmitter is built-in and requires no additional hookup.

Doorbell Transmitter #1003-1 or #1003-2: The transmitter requires installation by attaching it to the wiring of the doorbell chime. When the doorbell button is pushed, the transmitter will activate the Vibra-Call Receiver. This transmitter can also be ordered with a remote button for use in an apartment or motel.

Telephone Transmitter #1002-1: A dual connector, supplied, is all that needed to hook up a modular telephone to the phone transmitter. When the telephone rings, the electrical signal is sent to the Vibra-Call Receiver.

Sleep Alert/Charger #1006-1: This unit is not a transmitter, but rather a unit to which the Vibra-Call Receiver connects to at night. When a signal is received, a bed vibrator is activated. The sleep alert is plugged into an electrical outlet and also serves as a recharging unit for the battery in the Vibra-

## Call Receiver.

Pager Transmitter #1004-1 or #1004-2: This battery-operated transmitter is activated by pushing the Pager button. The signal is sent by the transmitter to the receiver, causing it to vibrate.

Sound Monitor #1005-1: Operating off either household current or a built-in rechargeable battery, this transmitter can be placed in any room to pick up sounds. This unit may be adjusted for sensitivity which allows for monitoring a wide variety of sound levels such as a baby's cry.

The entire Vibra-Call System can be purchased at one time, or is available in a basic system including the Vibra-Call Receiver, phone, doorbell and battery charger transmitter. Each additional unit may be added at a later time.

All Silent Call products are covered by a 2-year warranty for any defects in the material or workmanship. A copy of this warranty is enclosed with every Silent Call product and offers free repair or complete replacement.



For further information, please feel free to contact: Silent Call Corporation, P. O. Box 16348, Clarkston, MI 48016-6348.

## **HKNC'S FIRST HALLOWEEN FAIR DRAWS THOUSANDS**

By Barbara Hausman, Director, Public Relations



Client, Scott Wirth, from San Francisco, CA enjoys himself at the Fair.

The spacious campus of the Helen Keller National Center was the scene of the Port Washington community's first Family Halloween Fair on October 27th and 28th, sponsored by the Helen Keller National Center (HKNC) with the help of local volunteer groups including the Port LIONS Club, Columbiettes, Port Youth Activities, Singles for Charities and private and public high



schools.

Some 5,000 adults and children were drawn to the many activities planned for amusement as well as for information and education about deaf-blindness. Along with pony rides, a very scary haunted house, free puppet and



Young visitors at the Fair wait for their names in braille being prepared by Bob Smithdas with staff member, Ann Sedewitz, assisting. The visitors used the TelleTouch to communicate with Bob.



Mrs Sharon Sibigtroth, wearing blindfolds, and her daughter Alisha from Port Washington try playing checkers tactually in the Daily Living Skills Dept.

magic shows, musical interludes, and carnival rides and games, many folks had their names brailled by HKNC clients and volunteers, learned about communication methods, devices and new technology, and even simulated several daily living tasks wearing blindfolds and earplugs.



Susan Ruzenski, director of professional services, demonstrates the use of the Tele-Braille.

cookies made by clients in their "socialization" program and at the residence were popular items at the Bake Sale.

A trainer from the Guide Dog Foundation of L.I. demonstrated techniques of working with a dog and the Mill Neck Manor Foundation provided a hearing test van and audiologists to offer free hearing tests for adults and children.

Caramel apples and



The festivities were enhanced by colorful and creative costumes worn by some of the children, adults and HKNC clients and staff.

The Center's staff, clients and volunteers shared an exciting experience with their local communities and look forward to planning the 2nd Annual Family Halloween Fair in October '91.



Clients Linda Carter, Lance Kamaka and Don Achas and volunteer, Pat Padilla, (L to R) get into the spirit of the Fair with their creative costumes.



## HERE AND THERE

The National Braille Press, 88 St. Stephen Street, Boston, MA 02115, is now offering a helpful list of sources that will provide transcription services. **INDIVIDUAL BRAILLE TRANSCRIPTION SERVICES** lists fourteen agencies. The list provides the following information: agency name and address; phone number; contact person; method of transcription (typed, disk, scanner); paper type and size; price per page; and types of transcribing jobs (computer-related, mathematics, music, documents, etc.).

For a free copy of the list, write to National Braille Press.

\* \* \* \* \*

The Billy Graham Evangelistic Association is now providing its magazine, **DECISION**, free of charge to the blind. **DECISION MAGAZINE** is available in braille and on cassette tapes.

Requests for free subscriptions should be sent directly to: Billy Graham Evangelistic Association, 1300 Harmon Place, Minneapolis, MN 58403.

\* \* \* \* \*

Seeing Technologies, Inc., 7074 Brooklyn Boulevard, Minneapolis, MN 55429, has used, reconditioned CCTV's for sale. Prices range from \$695.00 to \$2,000.00, and the equipment was originally produced by several manufacturers. Equipment comes with a one-year parts and labor warranty.

Seeing Technologies will also trade Voyagers or Vantages for cash, or for discounts on Seeing Technologies' Seetec color or black-and-white CCTV's.

\* \* \* \* \*

Ann Morris Enterprises, Inc., now has two kits which may help to solve the problem of identifying food products or items of clothing.

One kit consists of plastic strips which can be brailled with the product's name. Each

strip has a hole punched at each end, and elastic cords can be attached so that the labels can be slipped around frozen food packages and canned or packaged foods.

Another kit consists of special plastic buttons which are color-coded with braille letters. The buttons have two parts: one part can be inserted into any clothing item, and the second part is pressed against it for a permanent bond. The kit contains a wide selection of colors, with several buttons of each color. The buttons can be used to identify colors for towels, scarves, blouses and shirts, coats and other items; they are durable and can be used in the laundry.

To order either kit, write to: Ann Morris Enterprises, Inc., 26 Horseshoe Lane, Levittown, NY 11756. Braille catalogs are available for \$8.00.



## SPECIAL NOTICE TO READERS

In the September issue of NAT-CENT NEWS we announced that, beginning with the January 1991 issue, an annual subscription charge of \$10.00 (ten dollars) will be charged for the magazine. Deaf-blind readers will continue to receive the magazine in braille or large-print without charge.

Because of the limited response we have received from the first announcement, we believe that many interested readers either overlooked the original notice or may have forgotten to send in their subscriptions. We are, therefore, sending out complimentary copies of this issue. If you are still interested in receiving NAT-CENT NEWS, please send in your subscription payment no later than April 15, 1991, or your name will be removed from our mailing list for future issues.

We wish to thank the readers who have already subscribed, who find NAT-CENT NEWS an interesting and informative newsletter and who continue to be deeply interested in the progress and achievements of deaf-blind people.

I wish to continue receiving NAT-CENT NEWS.

— Enclosed is my check for \$10.00 (American) payable to the HELEN KELLER NATIONAL CENTER for a 1-year subscription to the print issue of NAT-CENT NEWS. Send to: 111 Middle Neck Road, Sands Point, NY 11050.

— I am a deaf-blind reader and wish to continue receiving NAT-CENT NEWS free of charge.

— Braille

— Large Print

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_  
city, state, zip







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**NAT-CENT NEWS**

**HELEN KELLER NATIONAL CENTER  
FOR DEAF-BLIND  
YOUTHS AND ADULTS  
111 Middle Neck Road  
Sands Point, NY 11050**

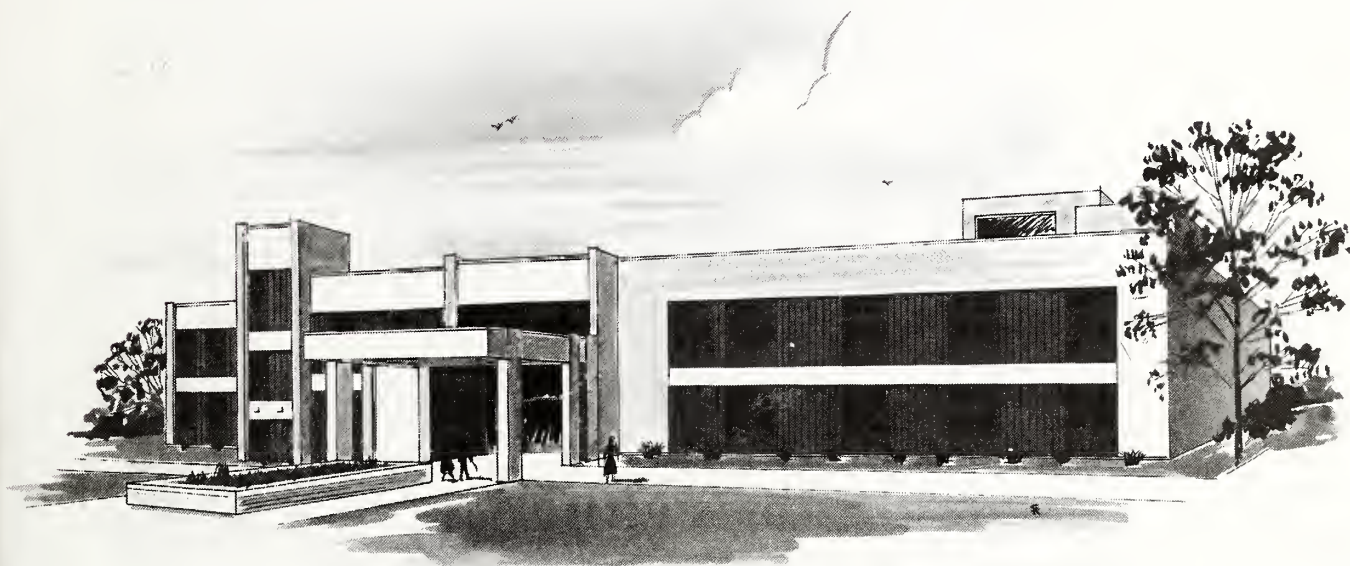
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**NEW OUTLOOK F/T BLIND  
A.F.B.  
15 W. 16TH ST.  
NEW YORK, NY 10011**

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# *NAT-CENT NEWS*



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**EDITOR — ROBERT J. SMITHDAS, L.H.D., Litt. D., L.H.D.**

**Editorial Assistant — Allison Burrows**

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May, 1991**

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## **EDITORIAL**

Information Please!

By Robert J. Smithdas, LHD, Litt.D., LHD

Recently I received a letter from a friend who is a certified Orientation and Mobility Specialist for the State of Maryland. Donna, who has worked with deaf-blind clients for several years, outlined a plan to develop a book describing O & M techniques that can be used with deaf-blind individuals. She pointed out that there was a need for professional literature on this subject, and that she had only found one published paper which specifically deals with the problems encountered by deaf-blind travelers. She requested my assistance with this project and, of course, I agreed to help.

This letter had the effect of reminding me again of how little published information exists concerning the specific techniques and methods used for the training and rehabilitation of deaf-blind persons. During the past forty years there have been surveys and studies of deaf-blind populations and



their needs, here and in other countries, but little has been written by professional workers about how they teach mobility and orientation, communication, skills of daily living, home management, sex education and other aspects of the training experience. To my knowledge, there is no major text that describes the emotional and psychological impact that losing both sight and hearing has on adults, and how they can be overcome or minimized through proper therapy and training. Though modern technologies have definitely added new dimensions to the lives of many deaf-blind people, there are no current catalogues or books that describe special aids and devices that can be used for solving some of the problems of everyday life for the individual deaf-blind person.

What is needed are books that detail techniques and methods of instruction for every aspect of the training and rehabilitation process, an international catalogue that provides descriptions of available aids and devices and their sources of manufacture, and a journal that provides a medium for the

exchange of ideas and experiences by professional workers and deaf-blind consumers.

We need manuals and reference works that detail and discuss the fine points of the training process and how they can be applied to individuals, and lists of resources that provide materials and services that are useful and viable for both professional workers and deaf-blind consumers. And ideally, such materials should be made available on an international level so that they can be shared and used for best results.

### **FIELD NOTES**

By Dennis Brady

Assistant Director - Field Services

It is springtime in New York. The seasons are changing. The flowers are starting to bud. Each day brings a few more minutes of sunlight. The smells of spring are all around us. The buds, the newly cut grass and the warm air make a special perfume that invites us to be outdoors. Springtime is often a

reminder of birth, of changes, of starting over. Springtime also reminds me that changing also means losing. Louis Anderson, one of our regional representatives from Seattle, WA, passed away on October 12, 1990. This is a change that saddens all of us.

Louis was by no means a saint and he would be the first one to say so. He was an ordinary person who lived his life in a fairly ordinary way. In the few months since his death I am amazed by the many ways Louis affected peoples' lives. There were no extraordinary stories. People remember his smile, his words, his hospitality, his friendship. One woman told me her interest in working with people who are deaf-blind began with a conversation she had with Louis. Louis' family had the chance to know more about him thanks to Sue Olson, our regional representative from Denver, CO. Sue collected pictures, notes and letters from HKNC staff and affiliates and gave them to Louis' family. I'm sure they had no idea how much Louis meant to so many people.

I think the lesson of springtime is the



lesson that life teaches us. Enjoy today! Enjoy all the little things! This is the lesson that Louis has taught us all.

\* \* \* \* \*

Please Note: Our office in the Great Plains Region has moved from Kansas City, Missouri, to: 5920 Nall Avenue, Suite 311, Mission, Kansas 66202-3456. (913) 677-4562.

**HELEN KELLER DEAF-BLIND**  
**AWARENESS WEEK, JUNE 23-29, 1991**  
**SHARE HELEN KELLER'S**  
**VISION. . .JUST LIKE THE LOMBARDI**  
**FAMILY!**

Agencies and organizations worldwide will celebrate "**Helen Keller Deaf-Blind Awareness Week,**" June 23 - 29. This year's focus will be on parents and their families who want the same thing for their child who is deaf-blind as Helen Keller wanted: **THE CHANCE TO LEAD A LIFE IN THE MAINSTREAM - THE RIGHT TO PARTICIPATE IN THE**

COMMUNITY, TO GET A JOB, TO FIND A PLACE TO LIVE, TO ENJOY A GROUP OF FRIENDS.

Mr. and Mrs. Anthony Lombardi and their 11 year old son who is deaf, visually impaired, and developmentally disabled hail from Ozone Park, NY, and are the 1991 poster family.



Originally proclaimed by Congressional resolutions and Presidential signatures in '84 and '85, activities and events featuring information about vision and hearing



impairments and/or deaf-blindness now occur throughout June and focus on the last week of the month around Helen Keller's birthday, June 27th.

The number of children and youth with deaf-blindness in the United States has been steadily rising. As of 1990, states estimate that there are some 7 - 9,000 children under the age of 22, though all concede that many youngsters have not yet been identified as deaf-blind, and others remain misdiagnosed. This doesn't include some 4,000 babies born deaf-blind during the mid-60's as a result of maternal rubella syndrome who have "aged-out" of the educational systems and are now, hopefully, in vocational rehabilitation systems. All urgently need or will soon need comprehensive, high quality, community based services, housing and jobs.

"The real social security for the future for our children is not an SSI check, but their ability to become members of their own communities," explains parent Valerie Dwork. "This provides parents with natural respite care, gives the community the opportunity to



care about their neighbor who is disabled, and empowers the individual to live a fully satisfying life."

Historically, many parents have felt frustrated and isolated. They needed information, direct support services, training and education, which could empower them to become articulate and effective advocates and leaders. Today, parents and family members, including siblings and grandparents, are working as partners with professionals and are becoming a more powerful force in establishing services to improve the quality of life for their sons and daughters who are deaf-blind.

Service providers, too, had to become more sensitive to parent concerns. Both groups needed to become more aware of how to plan and work together and how to promote interagency collaborative efforts.

A first step was made in January 1989, when parent leaders from 11 states met as an advisory committee at the Helen Keller National Center (HKNC) to form a NATIONAL PARENT NETWORK (NPN).

This national coalition of state organizations and individuals established a support system and clearing house FOR and BY PARENTS with sons and daughters who are deaf-blind.

Several goals were set and reflect global concerns such as:

- o The need for increased employment and community living options for those with the greatest disabilities.
- o The lack of training and resources to assist parents with stress management.
- o The need for mechanisms to identify and reach out to parents, particularly those with young children and those in rural areas.
- o The need for training to develop legislative advocacy and leadership skills, and an avenue for sharing the expertise of others who have been successful.
- o The need for accessible and current information including: medical issues, legislation, respite or home care, financial assistance, guardianship and trusts, new services and more.

"What the NPN means to me and what it says to me as a mother of a special daughter who is deaf-blind and multi-handicapped is HOPE, SUPPORT, INFORMATION AND ENCOURAGEMENT," stated one parent from Alabama. Parents who want to learn more about the NPN can call HKNC's special number: 1-800-255-0411.

All citizens, civic groups, libraries, schools and organizations are encouraged to plan state and local activities during the week of June 23 - 29. A sample proclamation, public service script, press release and 1991 poster are available from the Public Relations Department, HKNC, 111 Middle Neck Road, Sands Point, NY 11050, or call (516) 944-8900, ext. 325 (TTY & Voice).

### **HOSPITAL MAKES IMPORTANT GENETIC BREAKTHROUGH**

An important genetic discovery linked to hearing loss was made recently at the Boys Town National Research Hospital in Omaha, NE. A gene linked to Usher syndrome, a



disease that afflicts more than half of the deaf-blind people in the United States, was located by an international research team headed by Dr. William J. Kimberling, director of the hospital's Center for Hereditary Communication Disorders.

"This is a significant breakthrough in our understanding of one type of inner-ear deafness, which is accompanied by blindness," said Hospital Director Dr. Patrick Brookhouser. "It is the first gene associated with congenital hearing loss, and the discovery is a first step toward prevention and treatment of this devastating disorder. Our hospital's mission is not only to treat children with communication disorders, but also to develop new ways to diagnose and prevent these disorders. In the past, we have had to tell parents of children with inner-ear deafness that there is no effective treatment for their child. This discovery represents a ray of hope for thousands of deaf youngsters and their families."

"This is an exciting find," said Dr. Kimberling, who collaborated on the project

with Michael Weston and Yin Shugart of the Boys Town Hospital; Dr. Ira Priluck, Omaha; Dr. Claes Moller, Linkoping, Sweden, Dr. Richard Smith, Houston, Texas; Dr. Sandra Davenport, Minneapolis, Minn.; and Dr. Allesandro Martini and Massimo Milani, Padua, Italy.

Usher syndrome is characterized by congenital deafness or hearing impairment as well as retinitis pigmentosa, a form of progressive blindness. About 10,000 Americans have Usher syndrome, and the disease is responsible for about half of all deaf-blindness cases in the United States.

Usher syndrome Type II is marked by less severe hearing impairment than Type I of the disease, and occurs less frequently, Dr. Kimberling said. However, the discovery of the gene and continued research will help refine the localization process for both types of the disease, he added.

The gene was found by performing genetic tests on five families. It was localized in Chromosome No. 1, the largest human chromosome. The discovery was made at the

Boys Town National Research Hospital, where Dr. Kimberling heads a 10-person molecular genetics laboratory.

## **WOMEN WHO MAKE A DIFFERENCE**

By Gwen Yount Carden

(Reprinted from January 8, 1991, issue of FAMILY CIRCLE MAGAZINES  
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It had been months since Susan Allen slept in the comfort of her own bed beside her husband, and she knew tonight would be no different. Once again the exhausted young mother would spend the night on the floor, leaning against the door of her deaf and blind son's room so he could not escape.

That night, in the fall of 1984, Susan realized she had become a warden of love. She couldn't bear to lock 8-year-old Jake in, but she didn't dare let him roam around the house alone for fear he might hurt himself or others. Or else she could expect some ghastly surprise in the morning. More than once he flooded the house by turning on - and leaving on - the bathtub faucet. On other midnight



missions he emptied the contents of the refrigerator on the kitchen floor, and even broke into a neighbor's house and squirted caulking all over their furniture. Susan knew his wild behavior was the result of a kind of frustration she could never know.

But Jake did have many endearing moments, too. Sometimes he would lead Susan gently to the rocking chair, climb into her lap and wrap her hair around his face, enjoying the intimate smell of it and reveling in the comfort of her loving arms.

Sitting on the hardwood floor in front of Jake's door, Susan spent hours worrying about his future. What would happen to him when she was no longer around to protect him? Would he spend his days in some impersonal institution, strapped into a chair and medicated like a zombie?

In Jake's world there was no night or day, no good or bad, no order, no words. There was just endless, silent nothingness punctuated by unwelcome physical sensations - the startling arm out of nowhere to rein him in or the food forced into his mouth three

times a day that he didn't even know how to chew.

In 1976, Susan was just 19 and newly married. A few months later when she became pregnant, she also broke out in a rash. Doctors assured her that the bumps covering her body were just a "mask of pregnancy" and said not to worry. But in fact, Susan had rubella, otherwise known as German measles. How wrong the doctors had been, and what a terrible nightmare life had become for her and her family. Jake's devastating disability is one of the most severe consequences of rubella infection during pregnancy.

No one had been able to reach this handsome, intelligent boy. Since age 1, he had been in the public school system in classes for the deaf, classes for the blind and classes for the profoundly mentally handicapped, which he wasn't. There were no classes for the deaf-blind anywhere near Orlando, Florida, where the family lived, and a state-funded school in St. Augustine refused to accept him because of his behavioral

problems. Frustrated teachers tethered him to his seat and even slapped him when he screamed and disrupted class.

Discipline didn't work. "Punishment is only effective if a child knows he's done something wrong, but Jake had no idea he was misbehaving," explains Susan. In fact, by age 8, Jake hadn't learned a single word in sign language. Susan knew she had to do something - and fast.

From an education consultant Susan learned about a one-on-one technique used in Canada. While not popular in the United States because of its high cost, in Canada it is fully supported by government funds and has proved highly successful.

Even though she had no money and only a high school diploma, Susan vowed to open a boarding school for deaf-blind children. Armed with determination, she spent weeks at the W. Ross Macdonald School for the deaf-blind in Brantford, Ontario. The program was under the direction of John and Jacquie McInnes, pioneers in intervenor, or one-on-one, instruction.



Susan took their training course for intervenors and another designed for instructors. She learned exactly how the Macdonald School was set up and then followed it to the letter when it came time to organize her own program.

Some acquaintances allowed her to renovate an abandoned farmhouse in Zellwood, near Orlando, and use it as a school facility rent free. At first most of her volunteer help came from her church, but as word spread, people from all over the community pitched in.

When she needed something for the school, she just opened up the Yellow Pages and called local businesses until one came through. "I quickly got over being shy about asking for money or anything we needed," says Susan, now 34, and the mother of two other children, Jeremiah, 13 and Ellie, 9.

It was exciting and exhausting, yet there would be a price to pay. Her husband, Mike, a brick mason, was supportive and even agreed to sell their house for start-up money. But eventually their marriage fell apart. "I

had to choose between Mike and Jake - and I was all Jake had," says Susan.

She doesn't blame Mike. He wanted a wife at home - and she was too busy organizing auctions and addressing every group that would listen. Soon she was hearing from other parents of deaf-blind children who also needed help.

In the fall of 1985, the Jake Allen Center for Deaf Blind Children opened with three students and \$15,000. Susan initially hired seven intervenors through newspaper ads and trained them with the help of two experts from the Macdonald School.

"These people are the children's eyes and ears," she explains. "They get to know the children so they can interpret what their behavior and body language are saying. Language is what makes you human. It's language that stops horrible behavior, not discipline, so language is a priority here."

The intervenor is dedicated solely to one child in an eight-hour shift. By signing words over and over into the palm of the child's hand, she teaches him basic living skills and

tries to involve him in a variety of play activities such as swimming, jumping on a trampoline or walking.

"Intervenors can do this better than parents for several reasons," Susan explains. "Because they have no other distractions or responsibilities, they can be completely consistent and more attuned to the subtleties of the child's behavior. They can be firmer, and they're more realistic about the child's potential and his limitations."

Students are taught a crucial daily routine through a series of tactile "cues" that serve as a primitive calendar and give the child's life a sense of order. Before each activity a youngster takes a card from a peg and feels the object pasted on it. The head of a fork, for example, signifies time to eat. The intervenor also signs the appropriate word. Afterward, the card is dropped into a basket. When there are no more pegs, the student knows the day is over.

Up at 5 a.m. and in bed around midnight, Susan is mostly a fundraiser. Her school is now located in a white-pillared house (also



leased rent-free) next door to the original farmhouse. Parents are charged just \$416 a month for each child, although the annual cost per student is about \$60,000.

While she depends heavily on contributions from individuals and service clubs, Susan also has support from major U.S. corporations such as Walt Disney World, Tupperware Home Parties and United Parcel Service.

She has many admirers, among them Ronald A. Cyphers, regional representative for the Helen Keller National Center in their Atlanta office. "I'm excited that someone has provided an opportunity to deaf-blind children to learn and be independent," says Cyphers. "She stepped in when nobody else did and made a difference in the lives of these children. She's doing a wonderful, creditable job."

Despite the progress of many students, some educators have criticized Susan's maverick approach because academic subjects are not taught. Others say the program makes children dependent on an unnatural

environment. Susan disagrees: "It's more important to teach these children to care for themselves, to cook, have friends, do things they enjoy and make some kind of meaningful life for themselves. Academics can come later. We need to create a world for them that they can be happy in."

Some educators are also concerned that the school has not always had state-certified teachers on staff for the deaf-blind children. In fact, Susan has found that intervenors who are not professionally trained tend to be more receptive to the child and don't have preconceived notions about how deaf-blind children should be taught. However, three professionals will join the staff this January.

So far, 23 children have attended the school; 10 are there currently. Not every deaf-blind child can qualify. "We accept children with normal intelligence who haven't had such extreme environmental deprivation that they have no desire to learn," Susan explains.

Jake, now 14, has undergone an astounding metamorphosis. After washing the

center's van, he opens the refrigerator, pours himself some juice, serves himself spaghetti from a pot on the stove and sits down to eat. When he's finished, he rinses off his utensils and places them in the dishwasher.

He uses 500 signs and understands thousands. He leads a visitor to the school's backyard, where he has a tent he prizes. He carefully zips the tent closed so it stays dry. Susan is proud of his progress, though she feels he will need supervised care the rest of his life.

Before a child named Chrissy, 9, was enrolled, she constantly butted her head against hard surfaces and arranged different objects for hours in what is considered ritualistic behavior. She wouldn't feed or dress herself and was only partially toilet-trained. Today, however, Chrissy, also a rubella baby, is a calm, affectionate child who gets dressed and uses the toilet without problems, feeds herself and uses her minimal vision to draw and write the alphabet.

Such successes hearten and encourage Susan, especially during moments of



self-doubt or frustration. "There was a time when I begged God to give me the answer to unlocking Jake," says Susan, who plans to open an adult center soon and hopes to start schools all over the U.S. "I promised Him that if the answer came, I would spend the rest of my life doing it." And she is.

### **HERE AND THERE**

Planning details for a trip can be a problem, especially if the travel agent does not have an understanding of the needs of a deaf or hard-of-hearing travel to make the trip enjoyable. Here are some resources to help readers find travel consultants with sign language skills and TDD's.

American Express Travel Agency  
Travel Department for the Deaf  
1150 Connecticut Avenue NW  
Washington, D.C. 20036  
202-775-6900 (TDD)

Deaf Star Travel and Tours  
3400 Coral Way  
Miami, Florida 33145  
305-444-6383 (TDD)  
305-444-3538 (Voice)

Travel Agents International  
6138D Arlington Boulevard  
Falls Church, Virginia 22044  
703-536-5566 (TDD & Voice)  
800-486-2900 (TDD & Voice)

\* \* \* \* \*

A new network of people and organizations providing assistance to travellers with disabilities is growing across North America and overseas. Members of the network are willing to share knowledge of their home towns and/or provide other services disabled travellers might need. They also provide firsthand information to assure accessibility to facilities or extend services travellers might need in the event they encounter any difficulties away from home.

The two year old network is called "Travellin' Talk," and spans North America from Anchorage to Miami and Ottawa to Honolulu, with members in over 300 different locations. It also has members in China, India, Italy, New Zealand, Nigeria, Puerto Rico, South Africa and West Malaysia, and is growing. Membership in the network doesn't require having a disability, and remains free while its directory is being completed.

To keep members updated on the network's programs, introduce numerous resources available to travellers, and share tips and stories, they publish a quarterly newsletter which is gaining wide acclaim. Subscriptions to the newsletter are for any amount people are willing to donate to the effort regardless of how little, and is available in large print, braille, and cassette tape.

If you would like to join the network, subscribe to its newsletter, or be placed on the waiting list for its directory, send your name and address to Travellin' Talk, P.O. Box 3534, Clarksville, TN 37043-3534.

For information on planning a trip, call



the network's founder, Rick Crowder, 615-552-6670.

\* \* \* \* \*

Safeway Supermarkets now offers a home delivery system, Shopper's Express, in several states.

Affiliated stores offer same-day and next-day delivery of groceries and household items. The system is available in New Jersey, New York, Ohio, metropolitan Washington, DC, metropolitan Richmond, VA, Washington State and Oregon.

Shopper's Express is available to all disabled and homebound individuals; for blind and senior citizens, delivery cost is \$9.95 per order. For more information, or to place a grocery order, call 1-800-284-7467.

(Editor's Note: My wife and I have been using Shopper's Express for several months and we find it quite reliable. It is necessary to contact Shopper's Express through the relay services for the deaf, using a TDD or a TeleBraille.

(Many small local markets will delivery to homes when requested. However, such markets do not always carry the wide varieties of products that can be obtained through the large supermarkets affiliated with Shoppers Express.)

\* \* \* \* \*

A personal protection alarm called Echo (Emergency Call Help Out) is now available for those interested in personal security and safety.

The device, about the size of a TV converter, weighs seven ounces, operates on a 9-volt flat radio battery, and is housed in an almost indestructible Lexan plastic case. The alarm can be activated by pulling a ripcord which removes a pin from the unit, or by pressing a button. The alarm, operating at 110 decibels, is extraordinarily loud and can be heard for two city blocks - loud enough to scare off attackers, burglars, or call for help in emergencies.

Once the Echo is activated by pulling the

pin, it will sound its alarm for at least 15-20 minutes. The only way to stop the alarm is by removing the battery from the case and resetting it. The two-tone sound is overwhelming, and after a few seconds causes pain in the ears unless protected by covering.

Echo can be attached to a purse, briefcase, or other items which might be snatched from owners. It can also be used as a security alarm for doors by attaching it to the doorjamb with velcro, with the ripcord looped over the doorknob.

Echo is available for \$49.95 by ordering from: Personal Protection Systems, Inc., 200 East 33rd Street, New York, NY 10016, (212) 684-0030.

\* \* \* \* \*

Did you know that disabled passengers on Amtrak trains are now entitled to a 25% reduction, year round, on regular one-way coach fares. Call Amtrak for specifics.



## MAN OF VISION

By Fred Field

(Reprinted with permission from THE  
PATRIOT Ledger, Quincy, MA)

Foggy and quiet. Ernest Tracy of Sharon, MA, made the forecast for this Saturday several weeks ago. He knew he'd be right. Not a weather forecast, it was a personal forecast. Ernest is totally deaf, legally blind and thankful.

Tracy was born 48 years ago with Usher syndrome - a condition which involves deafness and a degenerative eye condition known as retinitis pigmentosa. "It's like looking at things in a fog," he explained. "Nothing is clear. I know if it's light or dark out, and I know if there's color." Ernest was "speaking" through his wife, Brenda, using tactile American Sign Language. Five feet away, their sons, Paul, 11, and Brent, 9, watched and listened. Their father couldn't see them.

Lack of sight and hearing have not stopped Ernest Tracy. Despite the

difficulties, he leads a full life centered around family, religion and work. "When I was growing up, I would feel discouraged that I was deaf and blind," he said. "I felt I couldn't cope with anything. I had no goals, I had no friends in deaf school at all." Ernest attended a special school run by nuns. "All the kids used to make fun of me and say, 'See, you're blind, ha ha ha.' I had no one to play with at all growing up."

Religion marked a double turning point. "After I started to learn the Bible, then I started to get a new feeling about the future - new goals. And my favorite scripture in the Bible was Revelation 21:4, where it said there would be no more sickness, no more death. And I know the Bible says I will see and hear again - this gives me hope."

Religion gave Ernest hope and something more. In 1974, a Jehovah's Witness met Ernest, realized he could not effectively communicate with him, and returned several weeks later with an interpreter named Brenda. Ernest converted to Jehovah and married Brenda.



For 22 years, Ernest has worked for Polaroid Corp. in Cambridge and Norwood. His current job is on an instant camera assembly line.



Ernest assembles instant cameras at Polaroid in Norwood, MA.  
Fred Field Photo

On a recent autumn weekend, Ernest was playing basketball with his sons. He takes all the foul shots. The boys help him aim before each shot, and indicate where his shots go by drawing a backboard with a finger on his palm.

"I don't want you to feel, poor me. People wouldn't feel sorry for me if they see



what I can do and my hope for the future," he said. "Most important to me is giving thanks every day of my life. I thank Jehovah all the time."



Paul tells Ernest the word he just made using tactile sign language during a game of braille Scrabble.

Fred Field Photo.

Ernest Tracy communicates and receives information in a variety of ways. Most commonly, the 44 hand shapes of tactile American Sign Language are used. This is how Tracy's wife and children typically talk to

him. For those who don't know tactile ASL, palm printing is common. Ernest understands letters traced on his palm, as well as braille and morse code "palm printed" on his hand. Co-workers at Polaroid speak to Ernest using palm printed letters.

A Telecommunications Device for the Deaf (TDD) enables Ernest to talk on the telephone. Ernest wears a small paper-like device that vibrates when the phone rings. He plugs the phone into the TDD and types each letter on a keyboard. This converts each letter to a sound for the person on the other end of the line. A major drawback is that the person on the other end must also have a TDD. Ernest receives their phone messages on a long, thin screen where words form one large letter at a time.

Much of what Ernest learns in printed form is through a closed-circuit TV device that provides high magnification of each word on a viewing screen. Ernest can also write, but this is tougher because he can't easily tell if he's writing over what he's written.



## **METAMORPHOSIS**

By: Gerald G. Purdy

Metamorphosis: to transform, change of physical form, structure, or substance; a marked and more or less abrupt developmental change in the form or structure of an animal (as a butterfly or a frog). How ironic this word metamorphosis, which so aptly describes a beautiful creature like a butterfly, also can be used to describe Usher syndrome Type II, a disease where one is born hard of hearing with later onset of retinitis pigmentosa. Usher II can have progressive hearing loss, possibly total deafness and eventually total loss of sight.

METAMORPHOSIS is also the name of a very special support group that meets in Seattle, Washington, an area that has many people with both types of Usher syndrome. Our group also has other visually and hearing impaired people who do not have Usher. Some are totally deaf and blind, but the one thing everyone has in common, besides varying degrees of deaf-blindness, is they are



all culturally hearing people and prefer to speak English.

Our group works hard to communicate as our individual needs differ. We use an assistive listening system called a "loop system" where we sit inside a wire which is like the wire on a telephone that plugs into the wall. The wire goes into an amplifier, a microphone mixer is plugged into the amplifier and then microphones are plugged into it. We take turns speaking into the microphones. Our hearing aids are then put on "T" switch or "MT" switch and the voices come into our hearing aids like talking on the telephone. One lady uses a Tellatouch machine where an interpreter sits at a typewriter keyboard and types what is said to her and she puts her finger in an opening and reads braille letters one at a time. Still another man uses tactile signed English with his interpreter. The ages in this group range from middle 20s to middle 80s.

People with Usher II have to deal with a loss of hearing and possibly complete deafness in later life. Unlike our counterparts with

Usher II, we have to deal with the loss of two senses we were born with and also the loss of our primary way of receiving communication from others. For people with Usher II it sometimes seems hard to get the services we need, why that is, I will not speculate on at this time. This support group (METAMORPHOSIS) has been very instrumental in helping me and others in coping with the constant changes in eye sight and hearing. This group has helped me to accept all the changes and to accept the white cane, which was one of the hardest things I have ever had to do.

In 1981, at the University of Washington Eye Clinic when I was diagnosed with Usher II, I finally knew what was happening to me. About two or three months later, I met Louis Anderson, the regional representative for the Helen Keller National Center. I did not know it then, but this man was going to change my life. Louis gave me all the information on Usher syndrome and his business card which I put in my wallet. I thanked him and he left. I could still see and

hear well enough to work at my job, so I didn't think of him again until the fall of 1988.

You see, in late summer of 1987, I was layed off from my warehouse job of ten years. For the next year I sat around home feeling sorry for myself. Then I remembered the card Louis gave me seven years earlier, pulled it out of my wallet and called him. We talked on the phone for about an hour. During this time he told me about his associate, Cathy Kirscher, and the support group, and the rest is history. Louis Anderson passed away in October of 1990, but on behalf of METAMORPHOSIS and the northwest region he work in, thank you Louis for enriching our lives and making the quality of life better for those of us who knew you.

### **A VALENTINE STORY**

(Reprinted from Soundings with permission  
of the Cochlear Corporation, Englewood,  
CA)

Our story begins in 1985. On June 5th of



that year, Jo Helen Mann became the first deaf and blind person to receive the 22 Channel Cochlear Implant. Blind from birth due to agenesis of the optic nerve, Jo Helen began to experience a gradual hearing loss during her teenage years. The cause was unknown. By 1977, she had lost all hearing in her better ear and could perceive only noise in the other; by 1980, she had lost even the ability to detect noise.

Jo Helen drew from a reservoir of spirit and determination, and spent 15 months at the Helen Keller National Center, developing communication, daily living and work skills. Soon after, she found a rewarding job as a teacher's aide at the Oklahoma School for the Deaf and Blind. With the support of "rehabilitation agencies, family, good friends and the community, I was able to achieve a fair level of happiness."

Approximately four years later, a friend encouraged Jo Helen to visit Baptist Medical Center in Oklahoma City to determine if she could benefit from a cochlear implant. She was indeed a candidate! After receiving her

implant, Jo Helen noted that, "Learning to use my new hearing effectively required time, patience and perseverance; but my effort has paid off wonderfully." She has found that she can usually understand speech both in person and over the phone, and only occasionally needs to ask the speaker to slow down. "Remember, I live in Oklahoma, and we all drawl, Y'all."

Meanwhile, Dr. Gary Fitts, a deaf-blind psychologist in Chicago, was considering a cochlear implant. Gary had gradually lost his sight beginning in 1965. Then in 1981, his hearing began to deteriorate rapidly. He awoke one day with no hearing in his left ear and 30% in his right ear. A year and a half later, he awoke with no hearing at all. When neither a definite diagnosis nor a medical solution could be found, he prayed for guidance to help him live as a deaf-blind person. For 6 years, he successfully managed his life and maintained a career as a writer, although "it was and is a struggle to be deaf and blind." In 1987, he began to consider a cochlear implant. The Mercy Hospital



implant team in Chicago counselled Gary conservatively, indicating that, although he qualified for an implant, they could give no assurance that he would be able to use the device without the benefit of lipreading. He responded to their concern, saying, "Don't decide for me what I can do; you don't know me."

While making his decision about the cochlear implant, Gary decided to write a letter to the author of an article written by a deaf-blind implant user: Jo Helen Mann. Thus began a correspondence which developed into a romance.

Within a year, Gary received his 22 channel implant. During his initial programming session, "Jo-ie" was by his side and spoke the first words through his implant, "Gary, I love you." "It was wonderful," he explained, "I could hear those words clearly and it meant that I could reach out and touch sound again."

In June, 1988, Jo Helen and Gary were married. In their life together, they have found that "we still goof up what folks say,



but sometimes it's funny; a sense of humor in any disability is essential." As Gary concluded, "We love life and love to hear."

(Editor's Note: In recent years there has been considerable interest in the cochlear implant operation. Prospective candidates for this operation, which involves implanting a tiny electronic device behind the ear to which a miniature 22 channel computer is connected, are carefully tested and evaluated prior to the operation, and there is no guarantee that the recipient will be able to successfully understand spoken language. Considerable time is required to adjust to the implant and to learn to distinguish sounds, usually under supervision of a qualified audiologist.

(Currently, there seem to be no firm statistics on how many deaf and deaf-blind individuals have received the cochlear implant, or information concerning the success of the operation in restoring useful hearing. This writer is aware that several deaf-blind persons have undergone the operation, but information about the results

is extremely limited. We would appreciate receiving comments from deaf-blind persons who have had the operation and the impact it has had on their everyday lives.)

## **NEEDS OF THE DEAF-BLIND POPULATION**

Following is a list of needs of the deaf-blind population which was compiled by Paul McGann of Pittsburgh, Pennsylvania, who was one of the earliest trainees at the Helen Keller National Center. The list is comprehensive and thought-provoking, and may serve as a reference for future guidelines in minimizing the unique problems of deaf-blindness.

\* \* \* \* \*

1. Counseling Services: Counselors need to have training in tactile communication and a better understanding of the psychosocial aspects of deaf-blindness, recognizing that this is a unique and diversified minority.

2. Job Placement: Support must be given to a deaf-blind person in locating job positions with follow-up services as needed such as interpreters for staff meetings and equipment to assist the deaf-blind person on the job.

3. Employment Guideline Handbook: A brochure which would be given to employers to provide them with communication methods and general information on deaf-blindness.

4. Consumer Committee: A group of deaf-blind consumers which would act as liaison with agencies and state offices in voicing the needs of the deaf-blind community.

5. Transportation: Statewide services should provide transportation for deaf-blind persons for jobs and job training, shopping, banking, and medical care. A workshop should be given to carriers to help them understand the needs of deaf-blind people.

6. Telephone Access: Special telephone equipment should be provided for deaf-blind persons, as well as 800 numbers that will provide relay service, information contained



in telephone books, weather and other essential information.

7. Interpreters: Work closely with state chapters of Registered Interpreters for the Deaf in educating professional interpreters to the needs of deaf-blind consumers; provide courses on deaf-blindness in conjunction with statewide interpreter training programs.

8. Guidelines for Schools: Teachers should receive training in the needs of deaf-blind students; schools should have mandatory eye examinations for deaf students.

9. Ophthalmologists/Physicians: They should be aware of the impact of Usher syndrome and retinitis pigmentosa; and in addition, be able to provide resource information to newly diagnosed patients.

10. Checkups: There should be annual checkups in schools for the deaf and schools for the blind to identify possible cases of deaf-blindness.

11. State Advocacy: There should be a support group for parents with dual-sensory impaired children, and support for siblings.

12. Devices: Equipment should be

provided for deaf-blind persons on a loan basis - TDDs, TeleBrailles, signalling systems.

13. General Public: Awareness information should be provided to schools for the deaf and schools for the blind, social clubs, and agencies to promote the inclusion of deaf-blind persons.

14. Repairs: Repair centers should be established to repair equipment (TDDs, TeleBrailles, etc.) and provide equipment on loan at no charge.

## **HKNC INTERN IDENTIFIES WITH THE WORLD OF DEAF-BLINDNESS**

By Barbara Hausman, Director of Public  
Relations, HKNC

She's animated, articulate, energetic and working successfully as a Gallaudet University intern case manager/counselor at the Helen Keller National Center (HKNC) headquartered in Sands Point, NY. Dorothy Walt happens to be deaf, vision impaired and has Usher syndrome - a genetic condition combining congenital deafness and

progressive blindness due to retinitis pigmentosa. "People with Usher are always changing - constantly adjusting," Walt explains. "What you can see today, maybe you can't see tomorrow or next week."

Born in D.C. and raised in Hyattsville, Maryland, Walt attended public schools and received speech therapy and lip reading training in special education classes. "I had a wonderful teacher through grade school. I'll never forget her name, Stella Lutz," recalled Walt. "We kept in touch when I moved away and I still remember what she looked like."

In high school she majored in commercial business and made the honor roll in her senior year. Even though she wore a hearing aid, at age 13 or 14 she could no longer hear the spoken word and at 15 couldn't use the telephone any longer.

Like every teenager, she was anxious to learn to drive a car and went for the required eye exam. "I had great central vision, I could see fine, I did everything like my peers," said Walt. "But I complained about not seeing at night and having some loss of peripheral



vision. Just a year earlier my older sister, Bernice, was diagnosed as having Usher syndrome. I guess it wasn't a total shock when I learned that I, too, had inherited the syndrome."

Undaunted, Walt pursued her interest in accounting/business administration at the University of Miami, where she was accepted for a one semester probationary period because she lacked college prep courses. After achieving academic success there, she transferred to American University in Washington, D.C., where she earned her bachelor of science degree.

Soon after marrying, she moved with her husband to Fairbanks, Alaska, where he was stationed for three years. After his tour of duty they moved to Juneau, Alaska, and in 1971, her lovely daughter Katrina was born. For 15 years Ms. Walt was chief financial officer for the Older Alaskans Commission where she was responsible for a yearly \$10 million budget in grants and state funds.

During the last five years in Juneau, her vision began to deteriorate rapidly. Unable to

lip read and enjoy groups of people anymore, she realized that she needed specialized training. HKNC's regional representative referred her to the Louise Rude Center in Anchorage for mobility training and braille study. "I met wonderful people. It was the first time I had socialized with people who are blind. It was a positive experience and I began to accept my blindness."

Looking toward the future and determined to fulfill an old dream, Walt sought a master's degree. Her daughter went off to the University of Oregon and she went off to Gallaudet University to pursue a graduate degree in Rehabilitation Counseling and to learn a new mode of communication, sign language. In January of her last year in the graduate program, she began her HKNC internship though she had already completed two other practicums - one at Gallaudet's Career Center and the other at DEAF REACH in D.C.

HKNC provides comprehensive rehabilitation and personal adjustment training, job preparation and placement for



all Americans who are deaf-blind. "This was the first time I had worked with people who are deaf-blind. Two years earlier at the AADB convention I met people with this dual disability for the first time. It was also the first time that I felt a sense of identity, and I could empathize with people who were feeling similar frustrations and had special needs."



Dorothy uses her sign language skills to communicate with one of her clients, Baila Weis, from New York.



On May 9th and 10th she will become the fifth person who is deaf-blind to earn an advanced degree from Gallaudet in the Rehabilitation Counseling program. With great confidence and sense of self, Walt speaks of her plans. "I understand how government works. I have many skills and experiences. I am interested in working with and for people who are deaf-blind in advocacy, education and program development. I want to work wherever I can be effective in improving the quality of life for people with this dual disability." Her personal philosophy is challenging. "One must be strong, be positive, learn to cope, adjust and accept your disabilities. But. . .support from people who understand you makes this a lot easier! Enjoy your life and live one day at a time.

## **THE WORK EXPERIENCE PROGRAM** **AT HKNC**

By Kathy Mezack, Placement Specialist,  
HKNC

Vocational evaluation and training of deaf-blind persons can be somewhat of a challenging task when working with individuals who have had very little exposure to any of the world of work's demands. The Work Experience Program at the Helen Keller National Center was developed to expose these individuals to a variety of realistic work settings. The Department's practices and procedures are based on an "adapted" supported work model in that the clients are provided with the intensive one-to-one support they may require to achieve some vocational success.

Although the Work Experience Department has a long history of providing on- and off-campus job training to many of our clients, some of the more challenged participants were not able to match up to existing work sites due to their skill or

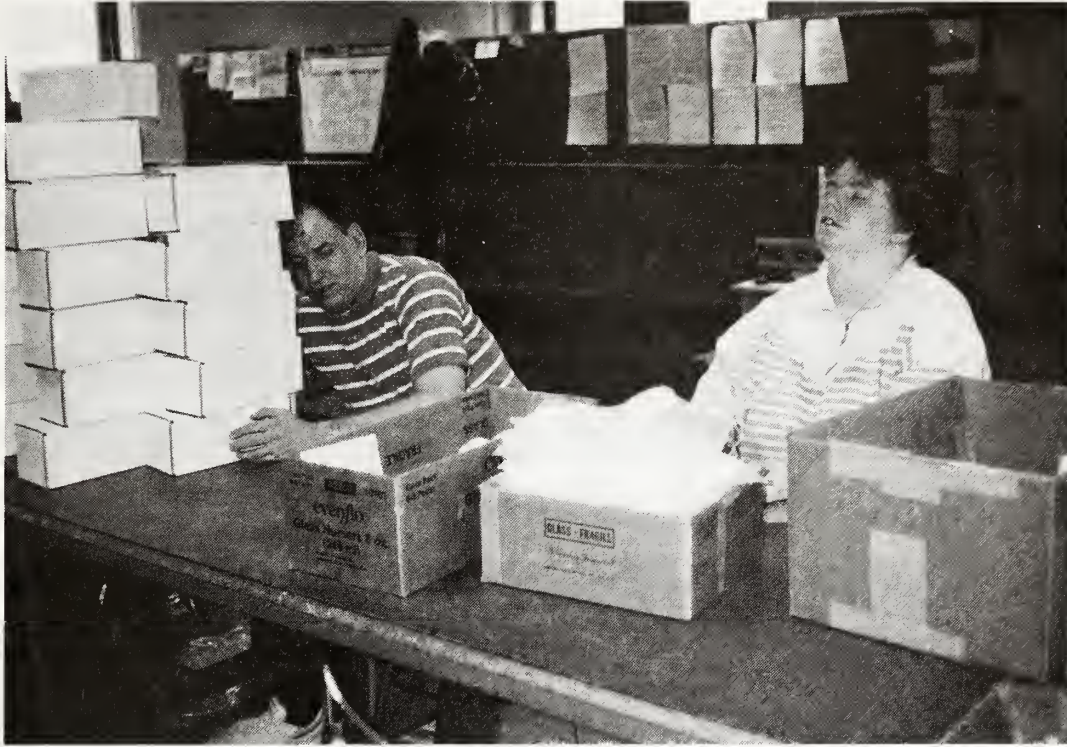
behavioral limitations.

The Department took on its newest challenge in December, 1990, with the development of an on-campus workshop. Formerly, clients were given vocational "exposure" through the efforts and creativity of our Pre-Vocational Department, which simulated various packaging and assembly tasks. Some of our clients responded positively to this activity while others preferred not to participate. How then could we get an understanding of all of our clients' vocational potential and, more importantly, their choices? Standardized testing may leave some questions unanswered, but the provision of functional work environments has a proven track record with many of our clients.

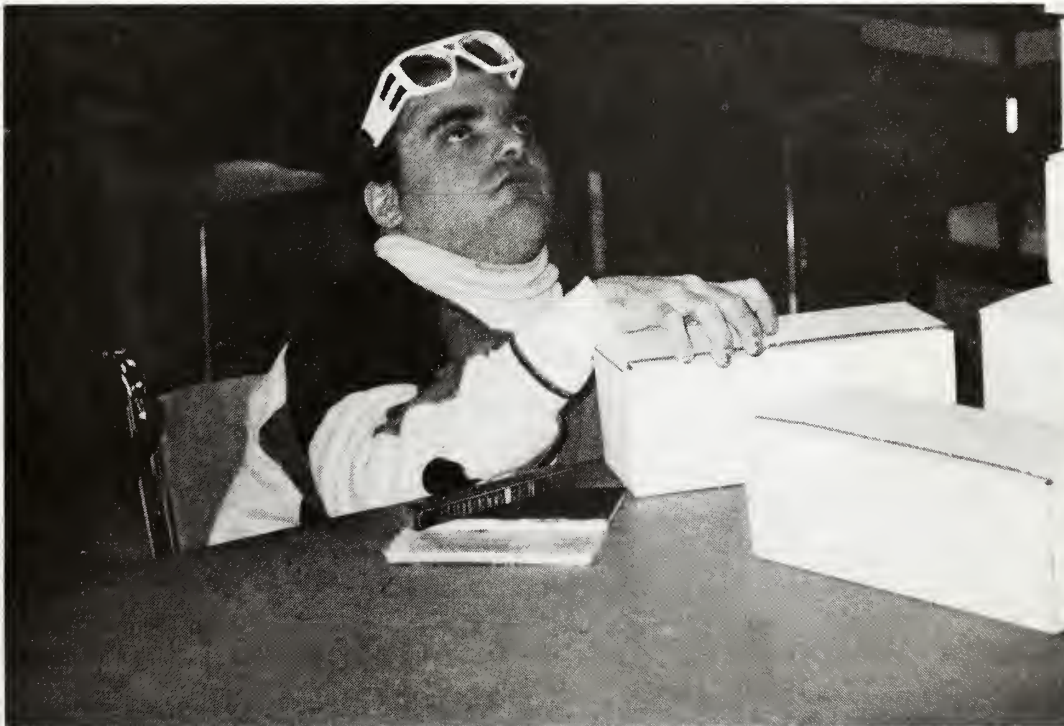
Our direction was very clear; we needed to bring "realistic work" to our campus so that the vocational process could start as early as possible. We have been fortunate enough to receive the cooperation of some local work providers, who have given us such tasks as the assembly and packaging of medical and beauty supplies, as well as the completion of



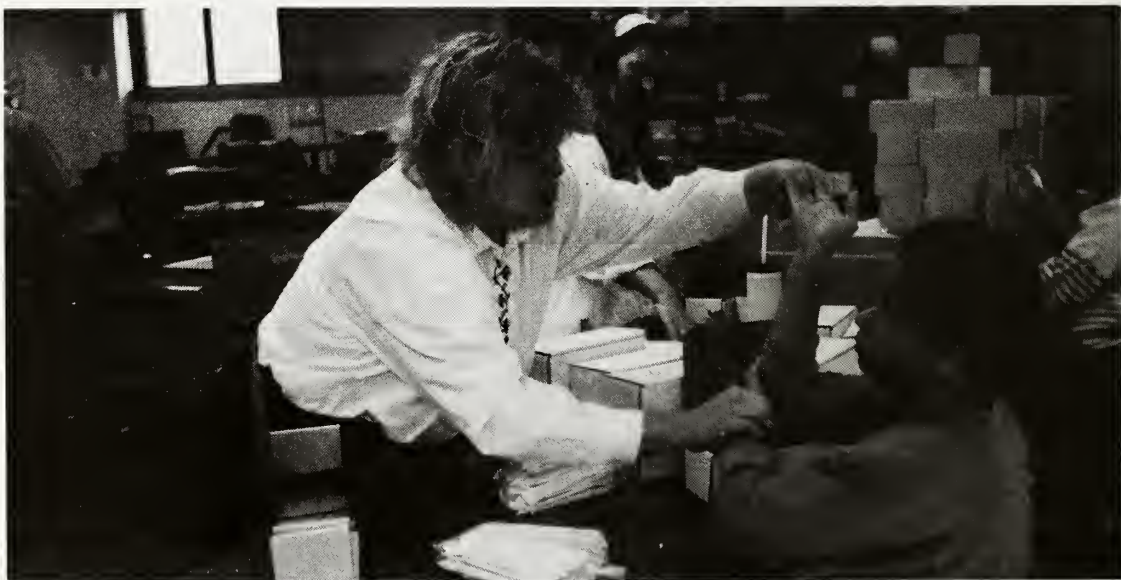
thousands of collating and mailing projects.



HKNC clients, Fred Diehl from NY and Joanna Egan from CA (above) and Steven Brown from NJ (below) are pictured at their packaging and stamping jobs on campus.



We also have developed our own on-campus projects, including: packaging silverware sets for use in our cafeteria, packing pre-measured laundry soap for our clients' use, and various landscaping jobs. Through the efforts of five of Helen Keller's finest job coaches, Helen Boystak, Theresa Hogan, Joseph Sampino, Valerie Stengel and Steven Zembrusky, our clients are being given the chance to make some of their own choices. Our job coaches are working very closely with each client, sometimes on a one-to-one basis in order to provide the training support needed to ensure some measure of vocational success.



Job coach, Valerie Stengel, works one-to-one with client, Paula Velez, from Hawaii.



In addition to skills training, the Work Experience Program is designed to provide the client with an opportunity to utilize their other training areas such as: communication, mobility, problem solving, and an orientation to the demands and challenges of the world of work.

With the assistance of the Communication Learning Center, we are meeting the challenge of creating opportunities for functional communication. Communication instructors are working closely with the Work Experience staff to develop individual communication goals. We are able to tailor the environment to give the client the opportunity to exercise choice as a preference or as a decision making process.

Clients are also learning the concept of money for work and are then able to develop and work on functional money management skills with the assistance of the Daily Living Skills Department. Reports from our Behavior Modification Department tell us that the number of problematic behaviors has decreased significantly since the inception of



the workshop. Our clients have responded very positively to being involved in meaningful work. Our success stories are adding up and I believe they will continue. The advantages to meaningful activity are clear. Clients are exposed to a more realistic work environment, develop a better awareness of the demands and challenges of work, and are able to develop some kind of work history to bring home with them to a permanent placement. We are best serving our clients by affording them the "functional" environment to develop to their fullest potential and meet that challenge for the rest of their lives. We are seeing new levels of motivation being shared by clients and staff alike.

## THE HKNC RAP

By Lance Kamaka, Client

REFRAIN: HKNC this is the place for you and me. It's the Helen Keller Center for the deaf and the blind. There ain't no place like it, it's one of a kind.

Hello everybody, My name is Lance. I'm gonna tell you 'bout this place if you give me a chance. There's a lot to learn and nice people to meet. And many other things that makes this place unique.

You got cookin' and cleanin' and job hunting too. If you lose your way - Mobility will help you through. You got HM, DLS, and CLC. I'm gonna tell you right now what all of this means.

First of all DLS, Daily Living Skills. Yeah I took this class and had a vibrating thrill. I learned to set the clock and alarm. And it wakes me up without doin' me harm.

Identifying money is a valuable skill. Using 5's, 10's, 20's, 50's, 100 dollar bills. By doin' all this I hope you understand. Doing it all independently is the plan.

## REFRAIN

Now CLC, Communications Learning Center. This will help you to change and change for the better. You will learn different ways to communicate. If you really wanna try it - don't hesitate.

You learn sign language, typing and braille. So you can write all your letters and put 'em in the mail. In computer class I am learnin' the Navigator. It's better than punching numbers on a calculator.

## REFRAIN

Now HM, Home Management that's the best. I'm learning how to cook my food without making a mess. I will tell you it's hard cause I'm not a fake. If you keep practicing, it becomes a piece of cake.

Ask and you will get it is the name of the game. If you take my advice you will never be the same. By doing all this I hope you understand. Doing it all independently is the plan.



There are many other things here that I'd like to cover. But I'm running out of time one way or the other. The counselors, the nurses and the residence staff. Well, maybe I'll put them in another rap.

REFRAIN.



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## EDITORIAL

### THE CHALLENGE OF THE ADA

By Robert J. Smithdas, LHD, Litt.D., LHD

A little over a year ago, President George Bush signed into law the Americans With Disabilities Act, a monumental piece of legislation which practically requires all employers and businesses to make their facilities and services accessible to disabled employees and customers. This law has the potential to change the way American society and business operate; it will change the way most businesses conduct their employment practices and what actions they must take to accommodate people with disabilities.

The process of developing regulations and guidelines to implement the law has already begun, and disabled groups throughout the country are actively discussing how the law should be used to accommodate the needs of people who are

disabled. There is little doubt that it will be several years before the Act is firmly established with dependable guidelines, but Americans are already becoming aware of its impact on community life.

Some examples of the new trend are that many restaurant chains are supplying menus in braille and large print to their customers; at least a dozen states now have relay services for deaf and deaf-blind TDD users; and several relay services are already able to make out-of-state long-distance calls for consumers. A few banks are currently testing services which provide 800 numbers for TDD users who wish to call their banks for immediate information about their personal accounts and investments. Several large brokerage houses based in the New York area also provide 800 numbers for financial advice and direct buying and selling of securities. Airlines, buslines, and Amtrak also have toll-free numbers available for disabled



travellers.

The law is already influencing business and services in various areas of the country. Well-known mail-order houses, including L. L. Bean, J. C. Penney, and Sears Roebuck, have toll-free TDD numbers so that hearing impaired persons can order direct from suppliers. A growing number of federal government agencies have also established such direct communication lines.

On a local level, here in the New York City and Long Island areas, NYNEX - the New York telephone exchange - and the Long Island Lighting Company will provide utility bills in either braille or large print. Several states have started supplying TDD devices to their deaf and deaf-blind citizens at no expense other than their monthly payments.

The Americans With Disabilities Act is so flexible that it is difficult to foresee what impact it will have on the lives of

disabled citizens in the next few years, and there is no doubt that the law will be vigorously tested as regulations and guidelines are developed. Because of its enormous potential, it will certainly have a profound effect on our attitudes about disabilities and the rights of the disabled, and will probably heighten public awareness of disabled groups and their needs for participating in community life on a more equal basis. And the deaf-blind population will be among them!

### FIELD NOTES

By Dennis Brady, Assistant Director  
Field Services

The Helen Keller National Center held its eleventh annual Affiliates meeting May 17-21, 1991. The turnout of participants for this occasion was quite impressive, considering the financial crises that many of the states are facing. Nineteen of the

Center's thirty-one Affiliates were represented at the meeting, as well as HKNC Regional Representatives, members of the HKNC Technical Assistance Center, the National Training Team, Placement Specialists, and its Specialist to Elderly Deaf-Blind Adults. Altogether there were over 40 people from the field services in attendance, plus many presenters who sat in on selected sessions, and members from the HKNC direct service staff who also attended when time permitted. Topics covered in this meeting ranged from technology demonstrations to information on AIDS; from augmentative communication to congenital rubella syndrome.

Feedback from the participants was, for the most part, positive and constructive. One of the suggestions that several participants made was that these meetings be restructured to allow for more exchange of information and ideas between



participants. Another idea that was favored by many was to aim for concrete results from these meetings; for example, develop a list of aids and devices useful to deaf-blind people and where to purchase them.

Plans for next year's (1992) Affiliate meeting are already underway. Because there will be a national conference on deaf-blindness in March - sponsored by the National Coalition On Deaf-Blindness, the Helen Keller National Center, and other interested groups - we are planning to hold the Affiliates meeting during the conference. The conference will be held in Washington, D.C., March 21-25, 1992. It is too early to say how the agenda and schedule will look, but information will be shared with the Affiliates and others as it becomes available.

Three major agencies have recently become the newest members of the HKNC Affiliate network. They are: New Jersey

Association of the Deaf-Blind, East Brunswick, NJ; Louise Rude Council for Deaf Adults, Anchorage, AK; and Deaf Reach, Washington, DC. Each agency will receive seed money over the course of the next five years.

This financial support enables each sponsoring agency to secure its own funding so that services for deaf-blind people within its area will continue.

The HKNC Affiliate program began in 1974 with one agency serving ten deaf-blind persons. Currently, there are 34 agencies serving more than 2000 deaf-blind people in 31 states. HKNC is committed to supporting efforts that give deaf-blind people choices of services in their home communities.

## PARTNERS IN SUCCESS

by Barbara Hausman, Director of  
Public Relations, HKNC

He worked as a printer in his home town, Las Vegas, for many years until his vision began to deteriorate. Born deaf, Richard Kelsey discovered during his middle years that he had Usher syndrome, a congenital condition combining deafness with retinitis pigmentosa. After the death of his wife, for whom he had cared so lovingly, Kelsey was alone. He soon realized that he needed to acquire new skills to continue to live independently and to cope with his vision impairment and possible blindness.

A little over a year ago, Kelsey entered the Helen Keller National Center's rehabilitation training program in Sands Point. He learned to "sign" tactually; he studied braille, typing and the computer; discovered he could travel alone using the



long cane. He even learned to cook safely. But a vital part of Kelsey's vocational preparation occurred at the Port Washington Public Library.



RICHARD works on filing updates in the Reference Room of the Library.

Since 1983, the library has successfully provided a variety of work experiences for Helen Keller clients. For many, this was a first "real" job. For others, like Kelsey, it was an opportunity to apply newly learned skills and prepare for a second career.

Twice a week Kelsey spent several hours fastidiously filing updates to library reference books. At first, an HKNC job coach accompanied him to the library, oriented him to the physical site and the specific clerical tasks assigned to him. "Soon he was totally independent, said his supervisor, Head of Information Services Priscilla Ciccariello. "He arrived and left by taxi, found his way to the elevator and the Reference Room, picked up his work at the desk and headed straight for the shelves."

If you plan to visit Las Vegas, you can look him up. He's now living independently, with some supportive health services, and will probably be found at the Imperial Palace Hotel working efficiently as



a file clerk. Partners like the library and other community "work providers" have helped HKNC to improve the quality of life for many of our fellow citizens who happen to be deaf and blind.

### DEFINITIONS

In recent years there has been much discussion concerning a general definition of "deaf-blindness" that would be acceptable to most countries providing service programs for persons who have the dual disability of deafness and blindness in combination, or who have such severe hearing and visual losses that they have the unique problems associated with the disability. To date, however, there is no universally accepted definition. What seems to be needed is a general consensus of opinion and agreement on the legal definition of blindness and the legal definition of deafness, and the final



phrasing of the terms to be used.

In the past, NAT-CENT NEWS has reprinted definitions adopted by various groups. In January of this year, the National Executive Board of Directors of the Canadian National Society of the Deaf-Blind (CNSDB) met in Toronto and drew up two definitions - one defining the term "deaf-blindness," and the other defining "intervention," the provision of needed services to people who are deaf-blind.

The CNSDB will use the following definition of deaf-blindness:

"A deaf-blind person is an individual with a substantial degree of loss of both sight and hearing, the combination of which results in significant difficulties in accessing information and in pursuing educational, vocational, avocational, recreational and social goals. Deaf-blindness is a unique disability requiring specialized services including adapted communication methods."

The CNSDB will use the following definition of intervention:

"Intervention is the provision of a professional service, paid or voluntary, to facilitate the interaction of a deaf-blind person with his environment. As a process of facilitating, the intervention can include translation, interpreting, transliteration, guiding and habilitation and rehabilitation teaching in the individuals' preferred adapted receptive communication methods."

### BRAILLE DAILY NEWS LAUNCHED FOR DEAF-BLIND CANADIANS

(Reprinted with permission from  
NEWSLINK, The Canadian National  
Institute for the Blind, B.C. - Yukon  
Division)

The Braille Daily News started arriving five days a week at the homes of eight deaf-blind persons in British Columbia

beginning June 24<sup>th</sup> to kick off Helen Keller Deaf-Blind Awareness Week in the British Columbia-Yukon Division. News items are sent to the Canadian National Institute for the Blind (CNIB) Transcription Services each morning from the CKWX News Room via computer modem, thanks to Campbell McCubbin, CKWX Morning Newscaster, and Chairman, CNIB Lower Mainland Communications Committee. The text of the stories are translated into braille and sent out by mail in the afternoon. It is believed that this is the first time in North America that electronic news is being produced and distributed in braille on a daily basis to deaf-blind persons.

It is also the first time that deaf-blind persons are able to access the news events taking place internationally, nationally, and locally. Previously, they would have had to depend on volunteer, Frank Van Rooy's, twice-weekly manual brailing of the news, or family and friends to tell them about the



events occurring in the world. Now they can read for themselves about the issues of Canadian unity, the intricacies of British Columbia politics, the route for the Richmond rapid transit, etc.

Deaf-blind persons depend on braille to gain information and knowledge. Modern technology is making it possible for them to be part of the community as was not possible during the lifetime of Helen Keller.

Other activities also took place throughout the British Columbia - Yukon Division during Helen Keller Deaf-Blind Awareness Week. This special week has three main objectives: to raise public awareness of the needs of deaf-blind people, to inspire more people to volunteer as intervenors, and to raise funds to buy much needed technical equipment for deaf-blind persons.

Nine communities throughout British Columbia and the Government of British Columbia itself, have proclaimed Helen

Keller Deaf-Blind Awareness Week. Proclamations were forwarded to the CNIB and were displayed during the week in the Vancouver Service Centre.

Canada Safeway Ltd. stores from British Columbia all the way to the Ontario border carried a message about the week on their milk cartons during the month of June.

The British Columbia and Yukon public were encouraged to understand what it is like being both deaf and blind via province-wide and Yukon radio announcements and community newspaper and magazine articles. As well, posters were circulated throughout the Division.

### A TALKING GLOVE?

At Stamford University in California, James Kramer, a graduate student in electrical engineering, and Larry Leifer, professor of mechanical engineering, have

developed an instrumented glove that translates the fingerspelling of deaf and deaf-blind people into speech.

Most deaf-blind people can neither hear speech nor see hand movements; many of those who are congenitally deaf, or adventitiously deaf from early childhood, have a little or no understandable speech with which to communicate. Many find it necessary to have words spelled into their hands with fingerspelling, or to follow sign language tactually. In contrast, few hearing people are skilled in fingerspelling or the use of sign language, and often an interpreter is needed for them to communicate with deaf or deaf-blind persons. But now Kramer hopes his "talking glove" will help nonverbal people communicate with all hearing people without interpreters.

The glove looks like a biker's glove without fingertips. Sensors are located over the fingers, the wrist, and the back of



the hand to detect movements in the joints. A microcomputer gathers information about the angles of the fingers from the sensors, then chooses the most likely letter from its preprogrammed hand formations. A straight hand indicates a space, telling the computer a word has been completed and to speak the word in synthesized speech which is amplified by a small speaker worn around the nonverbal person's neck.

A hearing person types his reply on a small keyboard about the size of a pocket calculator and a sighted deaf person can read the reply on a liquid-crystal display device on his wrist, similar to a wrist watch. Alternatively, a deaf-blind person reads the reply on a braille display worn at the waist.

In the future, Kramer hopes computerized voice recognition systems will replace the keyboard so that the hearing person can simply speak, rather

than type, replies.

Kramer has been trying to work out how the computer can decide whether the glove-user is spelling a letter, moving to the next letter, or just making random movements. He also plans to make the system less cumbersome by connecting the glove and display to the computer with infrared or radio links.

"The goal is to have the entire communication system portable so that it can be worn for daily interaction. The processing module can be worn on the belt like a radio and would be battery-powered," said Kramer.

Another future goal would be to have the glove system recognize sign language - a much more formidable project.

## DEEP IN THE HEART OF TEXAS

By Randy Feille, Texas Affiliate

According to Randy Feille, supervisor of

Deaf-Blind Services for the Texas Commission for the Blind in Austin, Texas, and a member of the Helen Keller National Center's Affiliate program, Texas has established a new Deaf-Blind Community-Based Apartments program for deaf-blind individuals who want to work competitively and live independently in the Austin area.

The project, established by the Commission, is the first in the state that provides 24-hour coverage to individuals who are deaf-blind and need limited assistance in working competitively and living independently. The community-based apartments are located in an existing apartment complex, allowing residents who are deaf-blind to live among other members of the community, and enhancing their ability to take part in the mainstream of society. In order to assure success, potential residents are provided training in their home areas by local Commission staff experienced in rehabilitation, as well as the



staff of the agency's Deaf-Blind Unit. More comprehensive training is then provided by the Commission's Criss Cole Rehabilitation Center in Austin.

"Ten individuals who are deaf-blind will have their own apartments through Section 8 of the Housing and Urban Development Program, and one apartment will be used for an office," said Bet Weatherhead, Deaf-Blind Residential Supervisor.

Training in orientation and mobility (cane travel), independent living (cooking, cleaning, budgeting, etc.) and communication skills (braille, sign language) are areas where assistance is offered before and during the apartment-living experience. Specialized equipment, such as telephone devices and signalling devices, are offered in the apartments and on the job to compensate for the individual's inability to hear and see.

"Statewide, there are approximately 3,000 Texans who are deaf-blind," notes

Mr. Feille.

For more information on the Deaf-Blind Community-Based Apartments program, or about services to persons who are deaf-blind, call the Texas Commission for the Blind at 512-459-2575.

### SLOW AND STEADY WINS THE RACE

By Peter Kreinbihl, Residence Director and  
Laura Rocchio, Assistant Residence  
Director

Meet the newest program at the Helen Keller National Center, the Supported Home Environment for Life-Long Learning program, or SHELL.

Mr. C. is a deaf-blind individual who has had limited life experiences. He exhibits some inappropriate behaviors that require constant monitoring by the Center's staff to ensure his safety and that of others. Mr. C. came to the Helen Keller National Center for evaluation and training to

prepare for an eventual group living situation and a possible job. Mr. C.'s evening and weekend routine required staff to provide one-on-one coverage to monitor his behaviors. He performed basic functional tasks on a regular basis (grooming, dining, laundry, room maintenance), and showed preferences for some leisure-time activities which he worked on repetitively in the lounge. But it appeared that opportunities for Mr. C. to exhibit his inappropriate behaviors increased, due to a lack of meaningful activities.

Monitoring Mr. C.'s behavior for several hours in a large open lounge with heavy traffic became an exercise in preventive techniques. Neither Mr. C. nor the staff were gaining benefits from the experience. For many staff members, Mr. C.'s behavior began to show liabilities, and they felt that because he could not be left alone, their goal to help him live more independently



was impossible. The idea of developing a structured, functional program to meet the needs of clients like Mr. C. was seriously considered. Such a concept had been suggested several times during the past few years, but now it took root, and the Center was ripe for its development.

It was decided that, in order to have such a program, it would be necessary to use existing resources. The "home environment" is one of the apartments on the first floor of the Residence. It contains a living-room area, bathroom, and kitchen-dining area. Staff persons were polled as to their interests and skills as related to working in the new SHELL program. The aim was to select staff members who could relate to clients in this program, and who could "connect" with them on varying levels. The staff now involved in the SHELL program is comprised of six members from the Residence staff and three from the Daily Living Skills staff.

SHELL staff are receiving ongoing training in the areas of communication, daily living skills, home management, behavior management, teaching techniques, leisure activities, and self-preservation.

The SHELL program formally began on May 6 of this year. Entrance criteria is flexible, intended to meet the changing needs of clients. The program currently includes the following:

1. The individual would benefit from a consistent 1-to-1 or 1-to-2 client-staff ratio.

2. The individual needs to develop a formal communication system based on his/her language development level.

3. The individual needs to develop preferences for leisure-time activities through exposure to a wide variety of experiences.

4. The individual needs to brush up and improve on previously learned skills to prepare for a group home placement.

5. The individual is entering HKNC and

has questionable skills which require close monitoring.

6. Skill acquisition would be enhanced through a "daily routine which is normalized, functional, and reappropriated, and provides limitless opportunities for learning." - S. Ruzenski

The philosophy of the SHELL program incorporates "person-centered planning." Person-centered planning creates and facilitates opportunities for people. It helps people to define their own lifestyles through choice-making. Another useful tool is the "personal futures plan," a format to help the individual determine a personal lifestyle and quality of life. The personal futures plan is a team effort by people who are involved in the individual's life; i.e., family, service providers, friends, volunteers. Steps include developing several maps relating to a personal profile, contributions, communication, individual preferences, image of a desirable future,



opportunities and obstacles, and short-term planning and planning strategies. The meetings are real brainstorming sessions to try to develop a plan of action to help the individual attain his/her desirable future based on all information collected. Personal Futures Planning provides an opportunity for one to really know the individual and to plan for him/her. It takes into account the individual's preferences and choices. It allows the individual to tell you through his/her language and behavior what is most important to him/her. It's up to the team to decipher that information and apply it in the most meaningful way.

The SHELL program also provides a more natural environment affording more opportunities for social interaction. Opportunities for communication are expanded and individuals begin to state preferences, make choices, and develop their own life styles.

The SHELL program incorporates many

areas of training in a realistic manner. These include personal grooming, eating skills, meal preparation, laundry, room maintenance, communication, socializing, leisure-time skills, money management, shopping, and accounting services. Currently there are five clients involved in the program - four men and one woman. Clients share all aspects of living together as a group, except sleeping quarters. Each client has his or her own room. The apartment is furnished in a warm, homelike atmosphere. Sharing and working together as a group fosters a lot of interaction among the clients.

Since Mr. C.'s entry into the SHELL program, he has been doing well. Occurrence of his inappropriate behavior has decreased; he is more motivated to try new skills and experiences. He currently has a loose-leaf notebook in which there is one full column of words which he will spontaneously sign in a functional

environment. There are two other columns of words he is working on to learn to use expressively and receptively. Staff have learned a great deal about Mr. C. - his abilities, his potentials, his preferences and inner character.

Mr. C. is involved in an environment that has meaning for him. Some of the things Mr. C. does that are meaningful to him are prepare his own breakfast, lunch, and snacks, and part of the dinner preparations (dinner is a team event for all clients). He attends class with the group and performs weekly chores. He goes out at least 14 times per week with a staff member, or with a peer and a staff member, and there are community trips that he enjoys. He is constantly expanding his life space with new activities people, and environments.

Mr. C.'s success and progress in this program indicates that there is a future for SHELL. But, as with any other new



program, there are still areas that need to be developed.

### HERE AND THERE

C O P I N G   W I T H   M A C U L A R  
DEGENERATION is now available in its second edition as an eighty-page large print book. It includes resource lists and references. To order, send check or money order for \$12.00 to: Vision Loss Technology, 4619 93rd Street, Lubbock, TX 79422. Telephone: (806) 974-6387.

\* \* \* \* \*

THE MADNESS OF COPING WITH VISION AND HEARING LOSS, by Dorothy H. Stiefel, provides glimpses of her early childhood and frankly discusses her life adjustment to a serious disability, Usher syndrome, Type II. Single print copies are \$7.50, plus \$2.00 shipping (U.S. and

Canada), or \$5.00 shipping for overseas orders (U.S. drafts only). Mrs. Stiefel, in spite of her disability, is successful as executive of a small publishing company, a housewife, and mother of six.

To order, contact: The Business of Living Publications, P. O. Box 8388, Corpus Christi, TX 78468-0388. Allow six weeks for delivery.

\* \* \* \* \*

A GUIDE TO HEALTH AND CONSUMER TOLL-FREE HOT-LINE NUMBERS is available in computer-assisted, hand-transcribed braille. In one volume, with 51 braille pages, the book is priced at \$10.00. To order, contact: The Beach Cities Braille Guide, P. O. Box 712, Huntington Beach, CA 92648.

\* \* \* \* \*

A check-writing guide which accommodates standard bank checks (2 1/2 in. by 6 in.) features slots for date, year, payee, dollar amount, memo section, and account holder's signature. Cost of the device is \$4.00, and checks should be made payable to: George Gray, 1002 Johnson Street, Pasadena, TX 77506.

\* \* \* \* \*

Peel-and-stick "Free Reading Matter for the Blind" labels, 1 in. by 2 in., are available at 100 for \$3.00, or 200 for \$5.00 from: Philip Chilton, 4895 Park Avenue, Nashville, TN 37209.

\* \* \* \* \*

Science Products offers Beamscope, a magnification unit designed to enlarge and enhance television pictures. Two models are available: one which fits 12- to 15-



inch screens and one which attaches to 17- to 19-inch models. Prices range from \$66.50 to \$77.50. To order, contact: Science Products, P. O. Box 888, Southeastern, PA 19399. Telephone: (1-800) 888-7500.

\* \* \* \* \*

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## THE LAZY, HAZY DAZE OF SUMMER

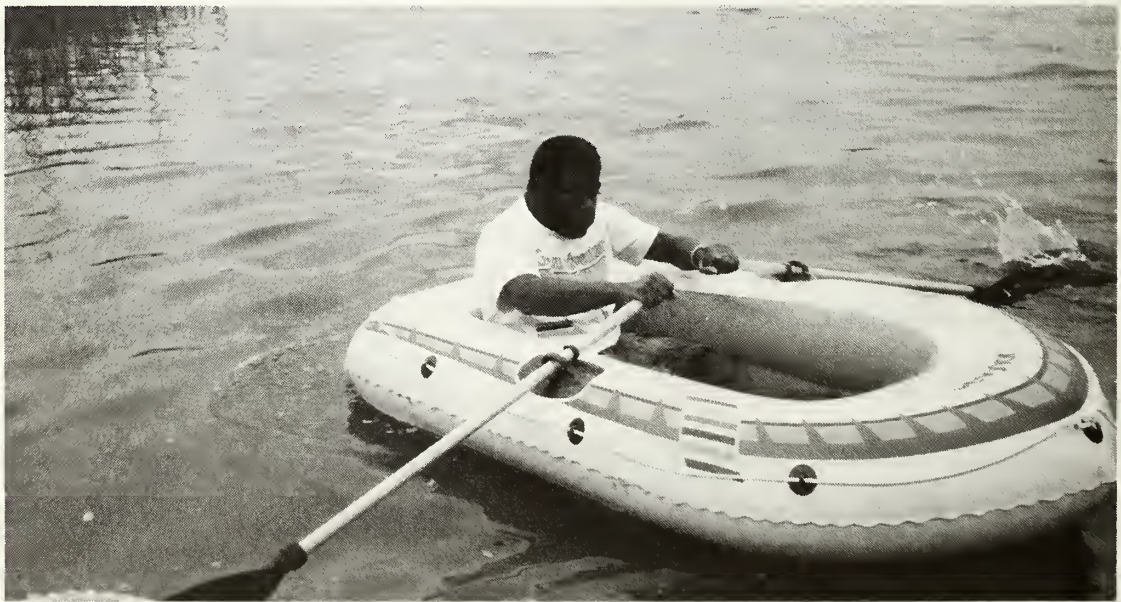
On a warm, cloudy morning in July, a vanload of clients and volunteers drove out of the HKNC campus and headed east to the forks of Long Island. By mid-morning they were at a ferry that would carry them across the bay to Shelter Island, one of New York's special summer retreats.

The eager group were the guests of Stella Haff and her family, who have vacationed on the island for years. Stella, who possesses a "green thumb," is a long-time active volunteer at the Helen Keller National Center's greenhouse. She volunteers in many other areas and is a member of the Friends of Helen Keller National Center, a group of community leaders who serve as a support system for the Center.

Soon the guests were preparing for the beach and the open waters of the bay. Just before noon, the sun broke through

the clouds, and the day was perfect! Some of the guests went swimming or sunned on the beach, others planed over the water in a speedboat, or rowed about in a dinghy. One of the guests was Sister Martha Henry, from New York, who is losing her hearing and sight, but not her enthusiasm for riding speedboats through curtains of salt spray!

After a picnic lunch the activities continued until it was time to return to the Center's campus. It was a unique experience for the group - and they loved it!

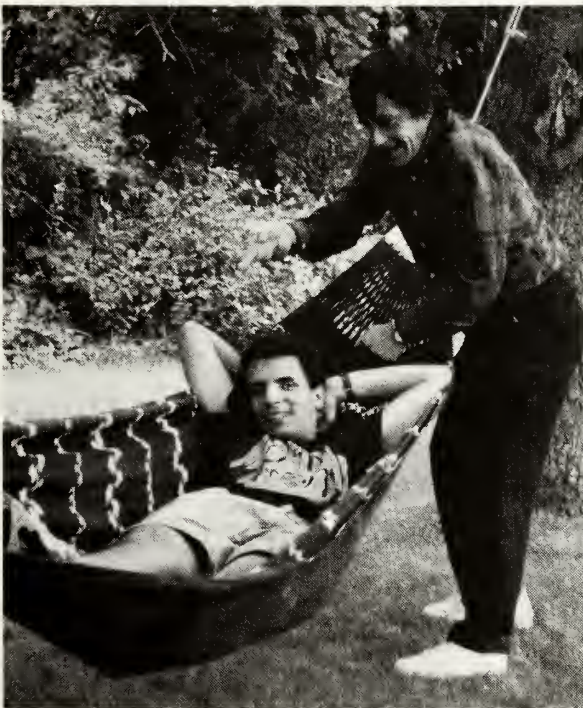


Client, DAVID BESS, from California, practices his rowing skills.





Sister Martha Henry, client (L) and staff member, Clare Szigethy (R) prepare to go for a spin in one of the rowboats.



Clients, MARCUS VELAZQUEZ, from Missouri, and GIORGIO BOTTIGLIERI, from New York, enjoy a swing in the hammock while client HENRY PALMER, from Pennsylvania, enjoys the company of Chelsea, one of Mrs. Haff's "grand" dogs.

YES, I HAVE USHER SYNDROME

(Reprinted from World Around You,  
May-June 1991)

Facing blindness was hard enough, but then Abby had to tell her friends.

Several years ago, Abby Strauss, a cheerful 13-year-old student watching TV in her family's home, noticed her eyes were not focusing. She went into the kitchen to tell her mother.

"My eyes are blurry," she said. "And I don't understand why."

Busy making dinner, her mother promised to call the eye doctor in the morning. "Maybe you just need glasses," her mother said. "Like your older brother."

Several days later, Abby found herself in the eye doctor's office.

The doctor prescribed glasses for her, but he didn't stop there. He also told her that she must see another eye doctor - a special eye doctor two hours away in



Louisville, the largest city in her home state of Kentucky.

Abby was puzzled. Her brother never went to see that special doctor. "Maybe he's just for deaf people," she thought. She never suspected she had a serious problem. "Everyone wears glasses," she thought.

A month later, as she entered the special doctor's Louisville office, she felt her first warning that something might be really wrong.

"The room was smelly and filled with old, sickly people," she said. "As I waited, I knew something must be terribly wrong with my eyes."

A "mean man" with reddish brown curly hair put drops in Abby's eyes to numb the eyeballs. Then a nurse put contacts in her eyes and forced her to lie down on a large table. A machine was placed over her body. Confused and scared, Abby lay in the dark unable to blink as the hard



contacts cut against her eyes. For 30 minutes, she stayed on the table, while the machine took its pictures.

When it was over, she was led to another room where another person put more drops in her stinging eyes. Then the doctor came in.

She disliked him immediately. "HI ABIGAIL, HOW ARE YOU DOING TODAY?" the doctor screamed at her.

Abby's mother explained to the doctor that it did not matter how loud he screamed, Abigail was deaf and would not hear him.

Then came more tests - reading the alphabet, picture taking. The tests lasted until lunch time. After lunch, came more drops and a final talk with the doctor.

Abby had no interpreter. She watched while the doctor and her mother talked. It was a long and serious discussion, she saw. Afterwards she asked her mother what the doctor said.

"The doctor is not sure what you have," her mother told her. "We will find out in about a week."

The week passed quickly. Abby's mom took her shopping for clothes to help her feel better. Then she was busy with school. Abby tried to forget about the unpleasant visit with the doctor.

But one night when she entered her parent's room to look for them, she found a piece of paper on their bed. At the top of the paper were very large words: "How to tell your child he/she is going blind."

Abigail froze as she stared at the letters. She put the paper back on the bed where she found it. She couldn't force herself to tell her parents she found it.

Alone, she wondered about the paper for several weeks. Finally, she saw her parents talking seriously in their room together. She walked in suddenly and asked "Dad, am I going blind? What is wrong with my eyes?"

Her parents glanced at each other, and then looked back at Abby. Her mother took a deep breath. "Abigail, sit down," she said. "I knew that what they would say would affect me deeply," said Abby.

Her father spoke first. He took a deep breath. Then he said, "Abby, you have Usher syndrome." Abby had never heard of Usher syndrome.

Her father explained that Usher syndrome is a genetic condition that causes a person to be born deaf and become blind. People who have Usher syndrome lose their peripheral vision. They get tunnel vision as the peripheral vision is continually lost.

The information was complicated and overwhelming. Abby couldn't quite understand what her parents were trying to tell her, she thought about it a week and approached her father again.

This time she asked him directly about blindness. Would she become blind?



Her father tried to sound positive. "Probably not for 30 or 40 years," he said.

Abby stared at him. "I left him thinking, why me?" she said later. "Why did this have to happen to me?"

In 1989, Abby left Kentucky to enter a program for gifted students at the Model Secondary School for the Deaf (MSSD) in Washington, D.C. "I was determined to keep my eye disease to myself," she said.

Abby remembered another girl she had known with Usher syndrome. The girl went to her school in Kentucky. She was a good friend and it had hurt Abby that the other students teased her.

"I recall one incident in math class especially," she said. "We were all sitting in a circle, and my good friend was reading her math book, when a boy from the opposite side called for her. He knew she had Usher and he did it anyway."

When she didn't respond to his first calling wave, the boy jumped and came

close to her, waving his hands around her eyes, jumping up and down, and testing how much Abby's friend could see.

"I saw the other kids giggling," said Abby. "Finally my friend looked up to see the other kids laughing at her because they thought it was funny. The poor girl was so embarrassed."

So Abby vowed to keep her problem private. "I was so scared of rejection," she said.

The fall passed quickly, but by winter, the other students began to notice that they would wave at Abby to get her attention and she would not see them. They began to suspect something was wrong. "Do you have Usher syndrome?" they asked her. "No," Abby lied.

They began to test her, just as she had seen her friend tested. Sometimes they did it as a group, bringing it up in conversation, and testing each other as well as testing her. Other times, they

tested her without her knowing it.

"It was just awful," said Abby. "I was so desperate. I would often fight back tears."

She saw a counselor. But the torment continued through the school year. Abby was finding it impossible to hide Usher syndrome from her friends and classmates. At MSSD, there were group meetings of students who had Usher syndrome, and Abby was required to go. She hated it.

Then came the week of the SAT's. The students' names were listed in groups.

"My name was with a group of brilliant kids," said Abby. "And I felt good."

But the next day a thick black marker struck through her name, deleting it from the list. Outraged, Abby went to the Counseling Department to ask why.

"'Oh you are MHHI (Multi Handicapped Hearing Impaired),' they told me so casually," she remembered still upset, hurt and angry about the unwittingly public



humiliation. The counselors had thought she would need more time and light to complete the SAT.

Strong feelings rushed through Abby. "I felt like screaming to the whole world 'I have Usher so the hell with it!'"

But she didn't. "Deep down inside, I was embarrassed about my eye sight," she said.

School ended. That summer Abby realized that facing her condition meant not just understanding it herself, but admitting it to other people. She would have to be able to work up the nerve to say to the other students, "Yes, I have Usher."

Abby returned to school determined and nervous. She was a little happy too, because at a recent visit to the doctor, she had learned that her eyes had actually improved.

When Wanda Riddle, her best friend met her again at school, Abigail's first thoughts were of her determination to tell

her the truth. "I thought how much she had hurt me the year before," she said. "I was determined to live through this. If no one was willing to be my friend because of my eyes, then they would not be my friends at all."

School was only in session a week before Wanda was asking her again about her eyes. "Abigail, please, will you tell me the truth?" Wanda asked.

"She looked tired of bothering me about it, so I just nodded and threw a stupid smile."

Wanda was stunned. "Are you serious?" she asked Abigail. "You finally admit you have it?" Abby nodded. Wanda turned immediately to the other students around them.

"Don't laugh," she told them. "Don't bother us." They didn't. Alone, Abby and Wanda went into a pizzeria and talked.

"Wanda really did understand," said Abby. "She said she would never, ever

desert me. She said having Usher is really no big deal, just something you have."

So Abby stopped denying she had Usher syndrome with the other students, too.

"They never, not once teased or tested me," said Abby. "They never made fun of me at all. "They respected me." Partly because of her own courage, partly because of the other students' support, Abby decided to tell other people, too.



CURTAIN

This Autumn world of red and gold  
is like a tapestry unrolled,  
with summer dying in a blaze  
of harvest colors, golden days.

And in my garden, all alone,  
one fragile rose is still in bloom,  
reminding me with its perfume  
of all the flowers that are gone.

And when it fades,  
I know that I'll remember  
the scent of summer roses in December.

-ROBERT J. SMITHDAS

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Due to increased costs of publication, distribution and postage, it was necessary to establish an annual subscription charge for NAT-CENT NEWS. All organizations, agencies, and professional workers are asked to pay a subscription of \$10.00 (ten dollars) per year.

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We sincerely regret this change of policy, but hope that our readers will understand its necessity.

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## **EDITORIAL**

### **TADOMA**

By Robert J. Smithdas, LHD, Litt.D., LHD

Recently, while reading an article discussing various methods of communication used by people who are deaf-blind, your editor came across the statement that Tadoma, a method of lip-reading through vibration, is "obsolete." Nothing could be further from the truth; Tadoma is simply not being taught to deaf-blind children in the schools that provide special education programs for them.

Tadoma was conceived and developed in the early 1930's, and the method was named for the first two deaf-blind students at Perkins School for the Blind in Massachusetts who learned to use it - a boy named Tad and a girl named Oma. Oma died while still quite young, but Tad (Winthrop Clark Chapman) is still alive and living in northern California. For over twenty years the method was taught to deaf-blind children at Perkins by three



dedicated teachers, then it fell into disuse.

Tadoma is a difficult method of communication to teach, and equally difficult to learn. The deaf-blind person's thumb rests lightly on the lips of the speaker, and the fingers rest against the side of the face and the throat. This enables the lip-reader to feel the vibrations of the vocal chords, the movement of breath, and the shapes of the speaker's lips when pronouncing words. Every sound in speech - consonants, vowels, and diphthongs - has its own characteristic combination of these elements, and the child learns to recognize individual sounds, and finally words, through repetition and constant



practice.

I was sixteen years old when I entered Perkins' department for deaf-blind children and began learning how to use Tadoma. The process was slow and tedious and required infinite patience on the part of the teacher and student alike. We were forbidden to use any other means of communication in order to develop sensitivity and skill in understanding what was said. In addition to reading lips, we also had to learn the mechanics of sounds in order to develop our own speech, and this required long sessions of practice with our teachers.

Tadoma has intrinsic benefits. It helps the child to realize that the majority of human beings use their voices to communicate; it aids in developing vocabulary and correct use of grammar; it stimulates an awareness of facial expressions and the emotions that go with them; and it assists in developing the student's own ability to speak. It is the only method that comes close to providing a direct oral

communication for deaf-blind people.

Tadoma is so unique that when it is used in public it attracts immediate attention to the persons using it. People wonder why the reader has his hand on the face of the speaker, and when it is explained that the reader is deaf-blind, observers find it mystifying that communication can actually be accomplished through such a method. The method seems almost magical to strangers.

Because Tadoma is no longer being taught, there are probably only six individuals who can use the method to advantage. Five are in the United States, and one is in South Africa.

### **FIELD NOTES**

By Dennis Brady, Assistant Director,  
Field Services, HKNC

These first months of 1992 have been quite busy and productive.

Everyone in the HKNC field services



attended the conference, "Deaf-Blind Services in the '90's: Revitalization and Future Directions," held in Washington, DC, in March. The national conference was the first meeting of this size held in approximately fifteen years, and was attended by 700 people. It was hosted by the Hilton-Perkins National Program with the help of many other organizations, including HKNC. The five-day meeting was attended by consumers, parents and family members, professional workers and special guests.

Each day of the conference consisted of a morning session devoted to one topic of interest. A keynote speaker addressed this topic and reactions were given by a panel made up of a consumer, a parent, an educator and a rehabilitation specialist. Each afternoon there were workshops and poster sessions. The topics discussed focused on every age group from infancy to older adults. Issues were related to education programs and adult services for the deaf-blind

population. Each evening was capped by a social event.

As time passed, people commented on how friendly everyone was and how exciting the programs were. There was a distinct sense of togetherness; people spoke of a momentum building, a realization of how much was happening in this country and other countries.

The conference concluded with a business meeting of the National Coalition On Deaf-Blindness. As a result of the excitement and networking that had begun on Friday, in a little more than an hour on Wednesday morning the National Coalition moved from a loose association of interested people to a welded group that agreed to elect officers, take on projects and try to meet every two or three years in a national forum. Before the end of this summer, membership in the Coalition will probably grow and officers will have been voted upon. This was a rousing finish to a stimulating conference.

Speaking of conferences, the HKNC will be

hosting the second national conference, "The Challenge of Independence: Vision and Hearing Loss Among Older Adults," on October 5, 1992, in Dallas, Texas. The conference objectives are: to provide information and skills that will improve services for older adults with hearing and visual loss; facilitate development of networks and coalitions among professionals working with adults who have sensory disabilities; and to heighten awareness of the needs of older adults with hearing and visual losses. For more information, contact Martha Bagley, Helen Keller National Center, 4455 LBJ Freeway, LB3, Suite 517, Dallas, TX 75244-5998. Tel.: (214) 490-9677 voice and TTY.

We are happy to announce that Kathy Kirscher, regional representative in Seattle, Washington, gave birth to a son, Dakota Sky, on April 4, 1992. Congratulations to Cathy, Tom and daughter Jordan!



## **HE VOLUNTEERS TO SERVE**

By Howard Tagg

(Reprinted with permission of the Buffalo Hearing and Speech Center, Buffalo, NY)

There is a special volunteer in the Deaf Adult Services at the Buffalo Hearing and Speech Center. His name is Raymond Boduch. Raymond, who was born on July 12, 1935, was enrolled at St. Mary's School for the Deaf in Buffalo, NY, at the tender age of 29 months. He attended Burgard High School to pursue a career in auto mechanics but had to discontinue this field of study because he was allergic to grease. In 1956, Ray graduated from St. Mary's and four years later obtained employment at Sierra Research in Williamsville, NY. While working, he attended an electronics training school in his spare time and became an electronics technician. Within time, Ray was forced to retire from Sierra Research after 22 years of service.

Raymond is a licensed ham radio operator as well as a computer whiz. You can always find him occupied with his two computers at his home.

What is so special about Raymond? Well, Raymond is both deaf and blind, and has been so since birth.

Raymond was fortunate to have Sister Aloysia as his special teacher at St. Mary's. She also taught another deaf student at the same time. Sr. Aloysia taught Raymond Tadoma which enables him to read lips through his hands. He is a member of a small number of deaf-blind individuals capable of utilizing this skill. He was awarded the Annie Sullivan Medallion in 1966 for his contributions to deaf-blind society.

Raymond volunteers his time to transcribe the Deaf Adult Services Quarterly Newsletter into braille for deaf-blind friends in western New York. In addition to this newsletter, he transcribes the Buffalo Civic Association of the Deaf and Buffalo Club of the Deaf

newsletters.

**SHARE HELEN KELLER'S VISION.....**

**By Helping Youth Who are Deaf-Blind  
Make The TRANSITION From School To  
The Real World**

Agencies and organizations worldwide will celebrate Helen Keller National Center's 1992 Awareness Campaign, June 21 -27, focusing on young people who are deaf-blind, as they make the transition from school or institution to life in the real world. New federal legislation emphasizes the need for services and programs which help all youth with disabilities become better educated, more employable, and live more independently as they leave high school and move on to further education, training or employment. For someone with severe multiple disabilities - including blindness and deafness - this is a herculean challenge.

Originally proclaimed by Congressional resolutions and Presidential signatures in '84



and '85, AWARENESS activities and events featuring information about vision and hearing impairments and/or deaf-blindness now occur throughout the year, beginning in June, since Helen Keller's birthday was June 27th.

Making the transition from high school to college, from high school to employment, or from college to work isn't easy for anyone in today's economic environment. But for young people with disabilities there is a new law to help with this transition, the Individuals with Disabilities Education Act (IDEA) of 1991. In IDEA, transition services are defined as a "coordinated set of activities ... including postsecondary education, vocational training, integrated employment ... continuing and adult education, adult services, independent living, or community participation." IDEA has mandated that transition services begin as early as age 14 and no later than age 16.

According to the HEATH Resource Center in Washington, DC, most of the 50

states have already passed legislation and begun to formalize ways to implement these goals - through interagency cooperative agreements, state transition councils, and technical assistance centers. On the federal level, the Helen Keller National Center's Technical Assistance Center (TAC), which was established in 1984 under a special grant from the US Department of Education, Office of Special Education, provides training, consultation and technical assistance to state and local education programs, adult agencies, interagency teams and parent organizations. TAC's goal is to assure that services flow naturally as youth "age out" of the educational system, where their rights to service are guaranteed by law, and move into the adult service system where services and supports are still developing and improving. TAC's desired outcome is an array of community based and integrated work, living, recreation and other community opportunities and supports which offer options and choices to youths with deaf-

blindness and their families.

## Sometimes, love is deaf-blind



Whatever the visual and hearing impairment, we help people like Linda Carter, and their families, make the transition from school or institution to real life in the real world.

Can we help someone you love? Call 516-944-8900 (TTY/Voice).

Share Helen Keller's vision.

Linda Carter, who is hard of hearing and legally blind, is a young woman in transition. While receiving rehabilitation training at the Helen Keller National Center in Sands Point, NY, she moved to an apartment in the local community with her six year old daughter, Meagan, independently pursued her role as a



parent, learned to manage her own household, and began an internship in horticulture, a field she loves. Carter and her daughter are the 1992 "AWARENESS poster" subjects.

All citizens, civic groups, libraries, schools and organizations are encouraged to plan state and local activities during the month of June, and **especially during the week of June 21 - 27.** A sample proclamation, public service script, list of suggested activities, 1992 poster and this press release are available at no cost from the Public Relations Department, Helen Keller National Center, 111 Middle Neck Road, Sands Point, NY 11050, or by calling (516) 944-8900 (TTY & Voice).

### **TOGETHER IN THE DARK SILENCE**

By Karen Uhlenhuth

(Reprinted with permission of the KANSAS CITY STAR, Kansas City, MO)

Every day, a blind and deaf Kansas City

area couple struggles to "be in the world". She gardens. He uses power tools. Together they've traveled the globe. Don't underestimate Leonard and Betty Dowdy.

Standing in the middle of his living room, sensing nothing but the air against his skin and the carpet beneath his feet, Leonard Dowdy is in a state of suspended animation. His arms dangle awkwardly in front of him. His fingers twitch as if he were playing cat's cradle with an invisible string. He's waiting for something. A visitor picks up his right hand as if it were a microphone and places it on her lips. His left hand reaches automatically for her throat and encircles it. She begins to speak. His slack face goes taut and suddenly his whole body is on high alert. His face beams with pleasure and gratitude.

Dowdy has just been plugged into the world. Leonard Dowdy is blind and deaf. So is his wife, Betty. Leonard, 64, lost his sight and hearing when he was 21 months old. Meningitis induced a coma and when he

awoke two months later, those senses had disappeared.

Betty, 67, was born deaf, but sighted. An inherited condition known as retinitis pigmentosa gradually destroyed her retinas and optic nerves. She and Leonard found one another in 1956 at a club for deaf people in Kansas City. Together, they've learned to feel their way in the silence and the dark.

Both are retired now, but for 35 years they worked and supported themselves. Betty folded linens at the University of Kansas Medical Center, and Leonard assembled vehicle safety lights at the Peterson Manufacturing Co. To get to work on time, every night they would "set" the vibrating mattress to shake them awake.

The squat brown house where they live alone in the Kansas City area is in immaculate order. Canned goods are lined up in the cupboards, peas in one row, tomatoes in the next. Braille magazines, National Geographic and Reader's Digest, are stacked



in the living room.

In their enclosed back porch, the Dowdys keep an electric toothbrush handy. It's wired into the system that alerts them to a ringing telephone or doorbell. When they sit on their backyard swing, Leonard puts the toothbrush in his pocket where its vibrations signal a caller or visitor.

The Dowdys are delighted with anyone willing to take the time and trouble required to chat. Both can speak, although they "listen" differently. Betty depends on words spelled into her hand either by sign language or regular letters. Leonard is one of a hand full of Americans adept at a system called Tadoma. By placing his hands on a speaker's mouth and throat, he can feel what's being said.

Their lives are about more than just coping, however. There is pleasure even in their sightless, soundless universe. Betty gardens, and for a time grew roses along with her marigolds, tomatoes and chrysanthemums.

"But the thorns," she said. "We hated those thorns." Leonard delights in his backyard workshop, and builds benches and birdhouses using an electric saw and drill press.

When they can find someone to read them the menu and help them navigate the table top, the Dowdys go out to dinner. They've traveled all over the United States, as well as to Europe, South America and the Caribbean. "They really are curious about the world," said Gertrude Sinclair, who taught Leonard at the Perkins School for the Blind in Watertown, MA, 50 years ago, and has remained a steadfast friend. She accompanied the couple on a trip to Europe in 1965. "They touched everything," said Sinclair, who lives in Waltham, MA. "They told us all about the bathroom fixtures." A photo shows Leonard standing at the base of the Cathedral at Chartres, France, reaching as high as he can on the wall. "The Dowdys are different. They are." Sinclair said. "But they are trying their best to be in the world."

Their most important conduit to the world is Barbara Brewer, their hired secretary and translator. Every Monday, Brewer helps them put their lives in order.

She has arranged to come at noon this day and the Dowdys have kept track of the time, running their fingers along the hands of the kitchen wall clock.

Suddenly and shrilly, the outside world intrudes. A grating buzzer rips like a chainsaw into the silence, a light bulb on the living room wall flashes and oscillating fans - mounted near the ceiling in every room - churn the air.

This orchestrated chaos means one of two things: the doorbell or the telephone is ringing. Within seconds Leonard has felt the air against his skin, and he edges his way along the wall to the front door.

It's Brewer. Leonard gladly claps his arms around her. For two weeks she has been gone on vacation, and the Dowdys have been adrift. The mail has stacked up, unopened, and the



grocery list - punched out in braille - has grown lengthy.

Betty offers to make sandwiches for the group. She opens the refrigerator and deftly pulls out the ham, lettuce and mayonnaise. That's the easy part. Programming the microwave is another matter. The braille stickers have fallen off a couple of the numbers and Betty's fingers do "loop-de-loops" before they finally settle on 2-0.

While the ham heats, she dips a spatula into the nearly empty mayonnaise jar and snares a thin ripple. She pats the spatula on the bread. Good enough. She takes the sandwiches to the table. Brewer picks up Leonard's hand and says, "I'm here, and Betty is across from you there."

Keeping track of each other is one of the Dowdys' daily challenges. "If I go from room to room and can't find him," Betty says, "I ring the doorbell and he'll feel the fans and go to the door. If there's no one there, he'll

go to the telephone and I'll be standing there."

At the kitchen table, Brewer sorts through the mail. She signs into Betty's hand, "Master Card - not a bill - a credit for \$72.78." Besides routine business, there's a crisis to resolve. The TTY, the device that converts into braille all messages that come over the telephone, has broken. One of the pinpoint-sized dots in its braille letters is missing.

With that, the tenuous thread connecting the Dowdys with the world outside has been severed. "We cannot read," Betty complains to Brewer.

Brewer calls the manufacturer in California, and signs the bad news into Betty's hand. The repair will cost between \$300 and \$800. Betty slaps a hand on her face and turns her head away in dismay. "Can you go without a telephone for five days?" Brewer asks Leonard. "That's right. OK," he responds in a lilting melody, nodding vigorously.

Wordlessly, Leonard reaches into a

drawer for a screwdriver, shuffles into a back room for the duct tape, and, unassisted, unscrews the lifeline from the wall and packs it into a cardboard box. For now, the Dowdys must wait for the world to come to their door.

The Dowdys find lifelines - especially the human kind - hard to come by. They spend much time alone, behind dark windows that contrast eerily with the warm yellow glow emanating from neighboring houses.

The mechanics of dealing with people who are deaf-blind deter many. "No one wants to take the time," said Bob Feinstein, a friend of the couple who is blind and lives in New York City. "Some people don't want Leonard to put his hands on their lips. It takes a special kind of person." Some of the Dowdy's neighbors, for example, have declined any contact with them.

The Dowdys have found friendship and support at the Deaf Liberty Baptist Church in south Kansas City. The minister and his wife, David and Charlene Hanson, who are both



deaf, regularly take the Dowdys to church and help them with errands and chores at home.

Yet the gulf is vast between deaf and deaf-blind people. "A lot of deaf people are not comfortable with deaf-blind people," Feinstein said. "Part of it is because sight is so important to them. It's a freaky thing to contemplate life without it."

That's why in 1956, Betty Kahn anticipated the possibility of a soul mate when she heard about a deaf and blind man in Kansas City. She lived with her family then, and every Saturday night went to the deaf club. But, she said, "You had to have eyes to know what they were talking about." By then, nearly all of her vision was gone.

One Saturday night, a mutual acquaintance took Betty to meet another visitor without sight. Leonard remembers he was sitting at a table when "someone came up and put my hand on her face and said, 'What is your name?'" Because this was a club for deaf people, Leonard assumed she could read

lips. "I told her, 'Leonard Dowdy.'" The woman clearly was confused. "I said to myself, 'She's handicapped,'" Leonard said, roaring with laughter. She was Jewish; he, Baptist. She was from a wealthy Kansas City area family; he was one of five children of a struggling railroadman and his wife from Sedalia, Missouri. She had graduated from Gallaudet University, a school for deaf people in Washington; he never finished the eighth grade. They clicked immediately!

"We talked and talked and talked for hours and hours," Betty said. "I found Leonard to be very bright and capable."

As they would later discover, they had met once before at the World's Fair in Chicago in 1933. Leonard, then 5, had been designated the Handicapped Baby of the Year. He was on display, demonstrating Tadoma with his teacher from the Perkins School. Betty, then 8, watched him, spellbound. "I was fascinated to see how he could read lips by touch," Betty said.

Sinclair likes to call Leonard the "eighth wonder" of the world. Although he wasn't always totally dedicated to his education at the Perkins School - he often pulled Sinclair in the direction of the school's horse, which he could smell from quite a distance - his mastery of Tadoma is remarkable, Sinclair said. "Everybody should know all about Leonard Dowdy."

The researchers at the Massachusetts Institute of Technology heard about Leonard and began flying him to Boston to study his method. They are trying to design a device capable of converting sounds into tactile impulses to aid deaf and deaf-blind people who don't know Tadoma, which hasn't been taught much since the 1950s.

When Betty met Leonard she recalled she was impressed not only with his communication skills, but also with his daring. This young man got around town alone on the public buses - or so he claimed. "I wanted to test him to see if he was telling me the



truth," she said.

She challenged him to meet her the next day at the corner of 12th and Main Streets. They found each other at the appointed place, and "stayed together for five months before we could marry," Betty said.

When she announced her marriage plans, her family wondered, "How are you going to get along?" said her brother, Lester Kahn. But Sinclair remembers the sparks, the silent, invisible sparks.

Shortly after their wedding, the couple visited her, and Sinclair drove while Leonard and Betty sat together in the back seat, conversing with their hands. "There would be silence, and then such giggling and laughing," Sinclair said. "They've got a good thing going. I hate to think how either of them would be without the other."

Between them, the Dowdys strike a certain balance. "Leonard's the stronger. He leads the way for walking and communication," said Norman Kahn, Betty's

brother. "Betty can do the planning, handle the money and make the decisions."

Leonard is exuberant, quick to laugh and quick to hug, and ever-ready to buy another tool at the hardware store. Betty is careful, more reserved, and keeps a tight grip on the purse strings. Leonard is known for his temper which can erupt when he searches for a screwdriver or braille measuring stick for 30 minutes and still can't find it.

At the Peterson Manufacturing Co., in Grandview, Kansas, where Leonard assembled lights for 35 years, he was known for his excellent work record - and for taking out his frustrations on inanimate objects. A co-worker, Francis McGee, recalls that when boredom overwhelmed him, Leonard "threw boxes of bulbs across the floor."

"He wanted to run the rivet machine," said Sandie Elkins, his supervisor during his last two years at Peterson. Although Leonard consistently exceeded the performance of his peers, Elkins said it wasn't feasible for him to

operate machinery. "He could get hurt. At times he's been very unhappy, frustrated and angry," Sinclair said. "But he still survives those times."

On the job and off, Betty and Leonard - especially Leonard - have labored against the constraints of other people's fears and assumptions. Although he wasn't allowed to run machinery at work, Leonard equipped a workshop behind his house with power saws, a sander and a drill press. The key to avoiding catastrophe he said is to "remember where my fingers are." He forgot once, and split his thumb open.

Their friends say the Dowdys will try almost anything. Leonard has water-skied, and once drove an off-road vehicle on his brother's Iowa farm. He held onto a 100-foot length of baling rope attached to a post and drove around in circles.

The Dowdys "love to do what normal people do," Sinclair said. "It means a great deal to their self-image. They are not



shrinking away or hiding. They are themselves. That's marvelous. There's an integrity about them...going through the world doing what they do the best that they can."

This fall, Brewer took the Dowdys to a riverboat party, a benefit for the Midwest Ear Institute. As the boat cruised the Kaw River, the Dowdys couldn't hear the country and western band, and they couldn't see the passing lights on the riverbank or the crowd milling about.

But at the auction table, as Brewer described the fur ear muffs and the belt buckle on display, the Dowdys caressed them, hungry for every detail. Then they toured the buffet table and felt the miniature corn, the artificial sunflowers, the roast pig. Leonard patted the pig from snout to tail, running his fingers inside the greasy crevice that had been sliced through the pig's back. "There's an apple in the tail. An apple!" He stomped his foot. He was positively gleeful. The servers looked on, clearly aghast.

But it didn't matter. Betty and Leonard were in the world, and they were having a fabulous time.

### A GIFT FROM GOD

Editor's Note: The following poem was written by Louise Catlin of Sun City, Arizona, who has a deaf-blind daughter who is a reader of NAT-CENT NEWS. It is a rare occasion when we are given an opportunity to share a parent's viewpoint.

\* \* \* \* \*

When evening comes and work is done,  
I sit to rest a bit  
and ponder on the things of life  
when all the lamps are lit.

I'm not alone, for there, close by,  
my precious one sits quietly.

She cannot see, nor can she hear  
sometimes she reaches out for me  
to know if I am near.

I take her hand, and then we say  
"I love you" in that special way  
the deaf sign with their hands.

She reads her braille while I read print.

I pause, and marvel she was sent  
to join our family.

Some years were hard and brought me pain,  
but later on, I saw our gain:

she's taught us much that we should know  
my life with her has made me grow  
in many different ways.

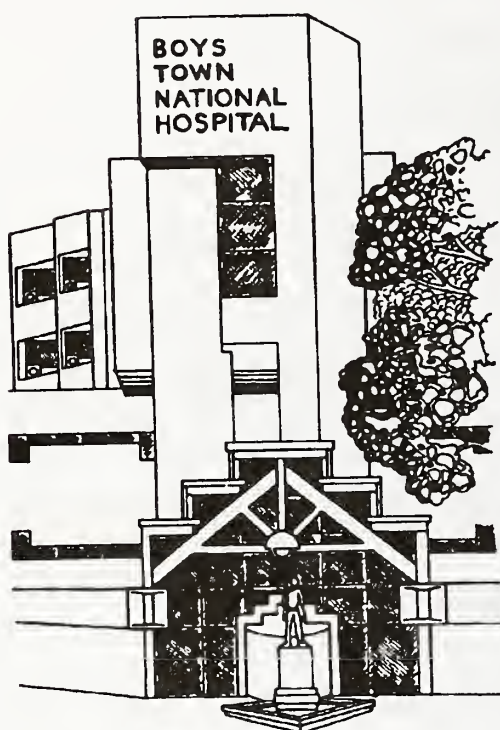
Although her birth was a surprise,  
she was God's blessing in disguise.

-Louise Catlin



## MORE ABOUT USHER SYNDROME

(From Boys Town National Research Hospital, Omaha, Nebraska)



Usher syndrome is characterized by congenital hearing loss, progressive visual impairment due to retinitis pigmentosa and variable balance (vestibular) problems. At least two genetic types of Usher syndrome are known to exist. The two main types, types I and

II, can be distinguished by the degree of hearing loss and by the presence or absence of vestibular dysfunction. Type I is characterized by a profound hearing loss and totally absent vestibular responses, while type II has a moderate to severe hearing loss and normal vestibular function.

The geneticists at Boys Town National Research Hospital (BTNRH) are currently conducting a study of Usher syndrome in an effort to locate the gene(s) which causes the disorder. In 1989 this research group, led by William J. Kimberling, Ph.D., localized the gene for type II. Their findings place the gene for type II on the distal one-third of the long arm of chromosome 1. Usher type II is the first autosomal recessive form of retinitis pigmentosa to be localized. It is also the first localization of an autosomal recessive gene causing deafness. This discovery is important because now the gene can be isolated and its mechanism of action understood. It might even be possible to someday treat or prevent some of the effects of Usher syndrome.

In conjunction with the RP Foundation and the National Institute of Deafness and Communication Disorders, a consortium was recently created with the goal of localizing the gene for Usher type I. In addition to researchers at BTNRH, the consortium

members in the United States include researchers at Baylor, Louisiana State University, the University of Iowa, the National Eye Institute and Gallaudet University. This collaboration will facilitate the enrollment of families with affected members as well as aid the collection of clinical information and subsequent DNA analysis.

Research on Usher syndrome depends upon the participation of families with Usher type I and II. To date more than 250 families have participated in this project with many families from Australia, Sweden, England, Ireland, Italy, Columbia and Indonesia. Dr. Kimberling's research group welcomes the participation of families with one or several members with Usher syndrome.

Participation involves completion of a family medical history form, release of medical records documenting the diagnosis of Usher syndrome and, in most cases, donation of blood samples by various family members.



There is no cost to participating families. If you would like to discuss participation in the research project please contact any of the investigators listed below: Dr. Kathleen Arnos, Gallaudet Research Institute, (202) 651-5258, Dr. Fielding Hejtmancik, National Institutes of Health (301) 496-8300; Dr. Bronya Keats or Dr. Mary Pelias, L.S.U. Medical Center (504) 568-8088; Dr. William Kimberling, Boys Town National Research Hospital (800) 835-1468; Dr. Richard Lewis, Baylor University (713) 798-3030 or Dr. Richard Smith, University of Iowa (319) 356-3612.

**SHE FIGHTS FOR RIGHTS FOR PEOPLE  
WHO ARE DEAF AND BLIND**

By Ann Chandonnet

(Reprinted with permission of The  
Anchorage Times, Anchorage, AK)

She's animated, articulate, energetic,  
empathetic and hard-working. She's  
counselor, Dorothy Walt, of Anchorage. Walt

is deaf as well as vision-impaired. At some point in the future she will be completely blind.

Walt has Usher syndrome, a genetic condition combining congenital deafness and progressive blindness. "People with Usher are always changing," Walt said. "What you can see today, maybe you can't see tomorrow or next week."

Attractive, slim, blue-eyed, Walt communicates by SIM-COM, an abbreviation for simultaneous communication. SIM-COM is a combination of signing and lip reading. Walt works at the Louis Rude Center For Blind and Deaf Adults on Gambell Street in Anchorage, where she is a counselor for persons with disabilities similar to her own. Her specific role is to coordinate the Deaf-Blind Affiliation Program. "There is a population of people who are hearing impaired only. There is a population of people who are visually impaired only. Then there is a third population of people that have

both impairments and therefore don't fit into either of the other groups. They have their own special needs, which have not been addressed adequately through deaf centers or blind centers," Walt said.

For such individuals, there can be gaps in services. "When they grow up and leave the school system of special education, deaf people or blind people go into a rehabilitation program at age 22. But for people who are both deaf and blind, there is often nowhere for them to go. That's where I come in." With the help of Assisted Technology of Alaska, Walt's first assignment was doing a survey on a random sample of the population. As far as she's been able to ascertain, Alaska has 432 hearing impaired people under 18, 3,199 age 18 to 59, and 2,810 over 60 years of age. Visually impaired Alaskans total about 605 under 18, 2,421 from 18 to 59, and 2,248 over 60. "I think those numbers are less than the real total because they skip households," Walt said.



Furthermore, the combination of legal deafness and blindness is something many do not want to admit. "Lots of people walking around fit into the definition of deaf, but they don't want to call themselves that," Walt said.

The national number is approximately 50,000 people in the United States who must deal with both deafness and blindness. Walt feels the true number is twice that.

Walt still has some vision perception, although clients need to scoot right up to her desk so she can read their lips. She is able to read some printed matter with the aid of a magnifying glass. Hearing aid amplification helps her to hear some environmental sound but not voices. "I was born hard of hearing but with perfect vision," Walt said. "I was diagnosed with Usher syndrome at 15 or 16, but called myself 'hard of hearing.' It wasn't until five years ago that I started saying I had Usher, which is a combination of retinitis pigmentosa and deafness." Usher is hereditary but often skips generations. One out of 100

people is a carrier of the gene but has no symptoms. For a child to suffer from Usher, both parents must carry the recessive gene for it, and then there is a 25 percent chance any one child will get it.

Ironically, Walt was prepared for her progressive sensory losses by the fact that she has a sister, 10 years older, with Usher. "I grew up with that and so I knew what would be happening to me 10 years later." Walt's sister is a bookbinder in Maryland and can communicate only by signing. Walt has one daughter, Katrina, 20, a communications major at the University of Massachusetts. Katrina does not have Usher but could be a carrier.

In addition to Usher, another common cause of deaf-blindness is congenital rubella syndrome, caused when a pregnant woman contracts German measles (rubella).

Walt is now putting together a comprehensive, statewide register of deaf-blind people who are 22 and over. "The

problem now is getting people to admit they fit that category. They won't come out of the closet. It's a real hard nut to crack. Most people are willing to admit just one disability." To break through this barrier of reluctance, Walt is using a series of public service announcements on radio.

Although people who are deaf-blind have difficulty holding down competitive positions, they often can do other types of jobs well. The goal of the Alaska Division of Vocational Rehabilitation is to get as many people working as possible, Walt said. Folding laundry at a hospital is an example of a non-competitive job.

Walt earned a master's degree at Gallaudet University, only the fifth deaf-blind person to graduate from the Graduate Counseling Program with a degree in Rehabilitation Counseling for the Deaf. She knows certain deaf-blind individuals who are thriving as medical researchers and counselors. "It just depends on the nature of



the disability and the personality of the person," she said. Once Walt completes her survey, she will go on to a younger population, children 15 and up. She will work on ensuring a successful transition for them from school district services to adult services.

Walt's position is funded by the Helen Keller National Center. The affiliate grant from the Center runs for five years, with decreasing amounts of money each year. The Department of Vocational Rehabilitation is also funding part of her position. "Alaska is different from other states because we are behind compared to New York and Washington," Walt said. "Part of the problem is the small numbers (generated by the small population)." In other words, it's easier to get grants and attention when you are dealing with hundreds of thousands of people rather than thousands.

Before she moved to Anchorage three months ago, Walt lived in Fairbanks for three years, and then in Juneau for 16 years. For 15

of those Juneau years she worked for the Older Alaskans Commission.

Counselors like Walt are few and far between. In fact, she knows of only one other deaf-blind coordinator who is actually deaf-blind in the nation. "Most graduate students at Gallaudet with me were hearing social workers," Walt said. Walt's own success encourages her to aim high for her clients. "I would like to see more deaf-blind people working at the management level," she said. "One of the reasons I am very excited about this job is that it will be a good role model for other states. Up until now, employers have been reluctant to hire people who are deaf-blind. I can make a contribution."

She attributes some of her success to her hard-working parents. "My father came to America from Poland as a young man, and my mother was first-generation Russian. They had a strong work ethic. My parents just let me do what I wanted to do, such as insisting on going to downtown Portland, OR, at age 8

on the street car. I was extremely independent and my mother just fostered that. I would have teachers tell me I couldn't go to college, and I'd just say, 'Who says?'" The University of Miami accepted her on probation as an undergraduate. When she got off probation, she transferred to American University. "And I haven't failed at anything yet," she said firmly.

Those who would like to register for the deaf-blind list should call 800-478-0501, or they can call via Walt's TTY number, 907-258-0510. Deaf Alaskans who do not have a TTY access can reach her through Alaska Relay Services. Dave Thompson, executive director of the Louise Rude Center for Deaf and Blind Adults, said a new federal law that goes into effect this year will require all states to have a relay service.

Thompson anticipates Walt's work will include setting up screening for Usher syndrome among 10-year-olds. "We want to make the public aware of the needs of the



deaf and blind community, and also of the services that are available."

### **DOING THINGS IN A DIFFERENT WAY**

By Barbara Hausman, Director of Public Relations, HKNC

"I didn't know that blind and deaf people could be very smart.... I think that deaf-blind people are a lot braver than us because having to live in the world and not being able to see or hear sounds is really hard to handle.... Thank you for teaching me what ordinarily happens in a blind or deaf person's life.... I still wish that people who are blind and deaf would not be that way...."

These are some of the comments third graders have made over the past year to two special volunteers from the Helen Keller National Center, Linda Stillman and Rita King. They have visited classrooms throughout Long Island to present a unique and compelling "hands on" program. Older

youngsters such as a ninth grade class of "children at risk" in Queens were very receptive and enthusiastic as well as a junior high class in Garden City.

The 45 minute program is presented to one class at a time in a school. It includes a description of a child's day at home and at school - but this child is deaf AND blind - and it includes the special methods and devices she/he may use. Mrs. Stillman, a certified brailist, prepares the class list in braille and each student tries out the Perkins Brailier. The youngsters learn to guide a blind person, try on glasses which



Using a white cane and a blindfold, a third grader experiences walking as a blind person.

simulate different eye diseases, walk with a white cane, and trail the wall - all mobility techniques. They try to read a braille magazine; play games which have been tactually adapted; learn some communication skills such as simple signs in American Sign Language, the manual alphabet and print-on-palm; handle braille watches and more.

"The youngsters are knowledgeable, sensitive and funny," noted Stillman. One told of her grandfather who couldn't hear her when she called him on the phone. Amplification from the New York Telephone Company was discussed and later implemented at home.

When one student asked if "people can tell if you can't see," Mrs. Stillman subtly identified this youngster as someone who was visually impaired and was mainstreamed in the classroom. She provided some written information for that teacher. In fact, bibliographies and guidelines on working with



youngsters who are blind or visually impaired, or deaf or hearing impaired, are distributed to all teachers at the conclusion of the program.

If you live on Long Island and wish to schedule this program in your elementary or junior high school class, your social or civic club, or would like more information on the program, please contact Allison Burrows at HKNC, (516) 944-8900.



Mrs. Stillman works with students at the Perkins Brailier.

### **A RAINBOW IN RUSSIA**

(Reprinted from The Journal of the International Association for The Education of the Deaf-Blind, January - June 1991)

Rainbow was founded in the spring of 1980 as an alternative movement to help the Zagorsk Home for Deaf-Blind Children in Russia. It is a non-profit organization, with over 10,000 volunteers helping with different parts of the program that it offers.

As part of the deaf-blind program, Rainbow organizes holiday tours for deaf-blind children from Zagorsk to different cities of the USSR. They encourage the teaching of English to deaf-blind children, organize summer holidays for children and parents, encourage the use of computers with deaf-blind people, and stimulate contact with foreign specialists in the field of social rehabilitation for deaf-blind people - especially those from England, Finland, Sweden and the USA.

Rainbow is an active member of the Family Clubs movement of the USSR. It also organizes a range of other activities for children and young people who have a wide variety of social problems.

### **POSITIVE SIGNS IN A SENSORY QUEST**

By Phyllis Stewart

(Reprinted with permission of the Erie Times, Erie, PA)

The robust 9-month-old bounces happily in his vivid red and blue portable swing, focused on things no one else can see, captivated by sound no one else can hear. Energetic and endearing, Tyler Smith presides over his childhood with an inner equilibrium, tinkering intently with the surrealistic terrain of his brightly colored play gym, chewing busily on the large red plastic key dangling in front of him, exploring the boundaries of his expanding world.

The equilibrium is deceptive. Blind and deaf since birth, the blond-haired, blue-eyed



Tyler is the focus of an aggressive and sophisticated effort to integrate him into his environment. Dominant in the effort are parents who are dedicated to his well being and willing to do whatever it take to foster his development. More that significant to its success are a battery of professionals - occupational, physical, and speech therapists, social workers, hearing specialists, an audiologist, a neurologist, pediatric ophthalmologists as well as a troika of advocates for people who are deaf-blind.

Tyler, the only know deaf-blind infant in northwestern Pennsylvania, receives regular occupational and speech therapy, has regular sessions with a teacher for the deaf and attends weekly sign language classes with his family. A vision teacher will join the ranks, and he will be evaluated by one of the country's few specialists in infant deaf-blindness.

Hardest probably for Tyler's parents, observes Julie Imig, a social worker with

Blindness and Visual Services, "Is to realize that they have to share him with so many other people." It is, however, just such early intervention that specialists agree is critical to the development of a deaf-blind child.

"The child who is impaired in both of those senses tends to get locked into a very solitary, isolated world," says Susan Kirshman, Ph.D., of the Pennsylvania College of Optometry in Philadelphia, a specialist in deaf-blind infants who will evaluate Tyler. "That child desperately needs intervention."

Ralph Warner of East Greenville, PA, president of the Pennsylvania Parents for the Deaf-Blind and father of an 18 month old son who is hearing and visually impaired, agrees. "The biggest challenge to the Smiths now is getting the correct services for Tyler," he says. It is a challenge made even greater, Warner adds, "because one of the big problems in the country is that there is little available for deaf-blind children age 0 to 3; there are no standards, no curriculum. After the age of 3,

a child can go to the Western Pennsylvania School for the Blind in Pittsburgh, Overbrook in Philadelphia or Perkins School for the Blind in Massachusetts, where Helen Keller went. But 0 to 3 are critical years in a child's development."

As a result, Tyler's parents are driven to secure aggressive intervention for their son. "The lack of knowledge is very frustrating," acknowledges Kristy Smith, Tyler's mother, a slim, dark-haired woman of 33 who spends much of the day with a phone warming her ear. As a parent you want that help and you want it now."

"In my mind, I wanted that deaf-blind specialist to be right there," she admits. "What really shocked me is when finally somebody was honest enough to say that nobody is going to come in and teach you how to raise that child. You have to learn how to raise a blind-deaf child by yourself. And that took months before I could get it in my mind. Who's going to teach me to teach him when



we're at home? And there is nobody."

"And I think the hardest thing in our life right now is you look a lot towards the future. Just the dumb little things will set you off. He's not going to see that. He's not going to hear that. How are the other kids going to react?"

The bottom fell out on a sunny day in May, 1991. With his mother hospitalized for thyroid surgery, Tyler was taken to an appointment with his pediatrician, Warren J. Beaver, M.D., by his aunt, Lynn Wickles. Concerned that "something was not quite right" with Tyler's eyes, she asked Beaver to check them. Kristy Smith returned home from the hospital only to be told that Dr. Beaver was "pretty much sure her son was 90 percent blind".

"My first reaction - the first thing I said was, 'Is he going to need glasses?'" she says. "We had noticed that Tyler's eyes flipped up and down. I was assuming it was because he was just 4 months old and he didn't quite

focus yet."

"The original reaction was disbelief. This can't happen to us, to me," Tyler's father, Loren Smith, recalls. A slight, soft-spoken man of 42, with an abiding gentleness about him, he adds that although he, like his sister-in-law, suspected something might be wrong with Tyler's vision, "When she said that he was blind it was kind of a tough one to believe. That feeling went right away, and it was more of, 'Well, what can we do to help him, to assist him and make his life better?'"

"It took awhile," his wife acknowledges, "for reality to set in. It was rough. It was quiet in this house for two days. Loren stayed downstairs and I stayed upstairs, because we didn't know what to say. Once we started the testing on him and taking him to doctors, we were fine."

Easing their acceptance of Tyler's blindness, says Imig, was the couples' commitment to the child. "They had been so committed to having this child, and their

bonding was so great in the beginning. It wasn't a fact of knowing this as soon as the baby was born and then somebody backing off rejecting the child. Many times parents do that and their children are affected," she adds. "But Tyler appears so natural."

What was to become a grueling odyssey began with a VEP (Video Evoked Potential) test at Saint Vincent Health Center designed to detect the integrity of Tyler's vision system, followed by a visit to child neurologist Joseph Barber, M.D. It continued with a referral to pediatric ophthalmologist, Dr. Kenneth Cheng in Pittsburgh. The outcome of the Cheng visit in early June was the determination that the tip of Tyler's optic nerve is too small. "Its real tiny," Kristy Smith says. "There's nothing surgically they could do."

In June, the Smiths returned to Pittsburgh where Tyler underwent Magnetic Resonance Imaging, designed to detect abnormalities in the structure of his brain, at Children's Hospital. The outcome was sweet.



"Tyler's brain was fine," Kristy Smith says. "No tumor, no cyst, no undergrowth or anything like that. If Tyler was seeing anything, Cheng felt it was shadows."

In July, Dr. Joseph Barber referred the Smiths to the Dr. Gertrude A. Barber Center, where a strategy for intervention began taking shape. They felt Tyler could use the services. They felt his motor skills and gross skills were a few months behind due to the visual problem. It was at that time, Kristy Smith adds, "That the hearing started being questionable but we kept thinking, no, that's how Tyler's doing everything he's doing. If he doesn't have the eyes, he must have the ears."

In July, Tyler's hearing was tested by Barber Center audiologist, Carol Barber. A second test by audiologist, Allison Keenan, followed in August at the office of Laser Ear Nose and Throat Surgery. The results indicated that Tyler was profoundly deaf.

"When the blind part came in that was devastating," Kristy Smith says. "When the

hearing part came in - that hit home. You already have one sense gone. The hearing was harder to accept and to handle than the blind part."

Loren Smith concurs. "Again I was very uh, oh boy, what's the right word? I don't want to say upset, but disturbed, discouraged, saddened, sorry," he says in his quiet way. "I just felt pity for the little guy. Now he's got two strikes against him right from the start. He's got a tough life ahead of him."

The couple, however, proved resilient. Quickly, "we both got over the sorrow stage," Loren Smith says. "You know, feeling sorry for him. In the couple of months since then, it's been much more positive. We know he can hear something with the help of a hearing aid. At least he can hear loud noises. The eyes, well, right in front of him he can see. Within two days, the sorrow was out of the way and we went on with our life, and it was all toward making Tyler's life a little better."

In September, Tyler was fitted with a

temporary body hearing aid. He is now awaiting arrival of a permanent pair of behind the ear aids. "He responded so quick to 'Tyler, Tyler,'" Kristy says. "He has loved the aid ever since. It's not off unless it's bath time or bedtime."

The full extent of Tyler's hearing impairment, however, has yet to be determined, audiologist Barber says, "because, as a result of his dual sensory loss he is difficult to test." On a scale of mild to profound, he has "at least a severe to profound hearing loss. The aids will basically make the sounds he hears (loud music, for example) louder," she adds. Tyler will also "be able to detect human speech," Barber says, although without some type of tactile communication - sign language - he will be unable to understand that speech.

As more is learned about Tyler's "basic threshold" of hearing, the aids will be adjusted. "He'll be able to hear more everyday sounds like dogs barking, phones ringing,"



Barber says. "Those sounds will bring him more in contact with his environment."

"He was very lucky to be diagnosed at such a young age," she adds. "He is in a critical learning period with speech and language. The sooner we can diagnose and intervene, the better off we will be."

In the meantime, in an effort to pinpoint the extent of Tyler's visual impairment, an extensive three hour evaluation was done in late August at the Western Pennsylvania School for the Blind. "They could turn off the lights and light a toy and he would respond to it," Kristy says.

A referral to Velma Dobson, Ph.D., an associate professor psychiatry/psychology at the University of Pittsburgh, followed. That visit, during which a visual acuity test was conducted on Tyler, had its positive side. "They felt Tyler could see your eyes and your ears and your nose." Kristy says. "I have to go with them. How can he reach up and just grab this? Or if you hold up his food that he

can try to grab it? He may not see colors or whatever, but he's got to be at least seeing shapes - enough where he might be able to get around without falling down the steps. I feel his eyes are a little better than his ears."

Recently, the family traveled to Cleveland, Ohio, where Tyler was examined by pediatric ophthalmologist, Ronald Price. The appointment reinforced the Smith's belief that Tyler has some degree of sight, and they were given a prescription for glasses. "The doctor does not know if they will help," Kristy Smith admits. "He believes Tyler is seeing something, but very, very blurry."

Although unflinchingly optimistic, the Smiths indicate that the stress, tensions and uncertainties of the past few months have taken a toll. Evenings at 8 o'clock as Loren Smith, plant engineering manager at the Parker White Division of PHB Inc., reads to the couple's 3-year old son, Steven, his eyes are sometimes red-rimmed, his face etched with fatigue. As Kristy Smith prepares Tyler

for bed, dark circles underline her eyes.

"The hardest thing is - at least for me - the constant. Everyday there's something going on." Loren Smith says. "It's either an appointment here, an appointment there, or we have to call this doctor, or we have to take him there, or we have sign classes on Wednesdays, etc. That's not bad by any means. It's just that our whole lifestyle has been changed now, and it's all around Tyler. And that takes quality time from Steve. That's really been the hardest thing for me personally, the change in your whole lifestyle."

"Sometimes you don't want to talk about Tyler," Kristy Smith admits. "You're trying to block him out but you don't block him out. That's the killer." The greatest adjustment, they agree, has been made by Steven.

Once the children are asleep, evenings are spent pouring through the foot-high stack of literature they've amassed on deaf-blindness and related issues; absorbing the intricacies of Act 212, the Pennsylvania



Regulation for Early Intervention Services, which details what intervention Tyler is entitled to under the law. Until he is 3, the cost of those services (including evaluations, therapy, materials, books and transportation) will be paid for by the Department of Public Welfare. The State Department of Education will assume financial coverage from 3 to 21. Income is no criterion for services under Act 212, which was signed into law by Gov. Robert Casey in December 1990. Tyler's medical care is covered by the family's health insurance plan, and an \$850 grant from the Loyal Christian Benefit Association will cover the cost of his hearing aids. Throughout it all, the family has had the support, and Tyler has had the acceptance, of Loren Smith's teen-age daughters by a previous marriage and of Kristy Smith's parents, Irene and Nick DiRienzo, and her five siblings. They have won the initial skirmishes, if not the war.

It is 11 o'clock on an October Indian summer morning and Barbara Eck, a Barber

Center teacher of the deaf, arrives at the Smith's comfortable, split level home in Millcreek. She will spend the next 60 to 90 minutes working with Tyler and his mother on a series of exercises designed to "establish a language base" for the child.

"We are looking at his needs in terms of communication." Eck explains. "At how we can let him know what's going on in his world. They're trying some gestures and touch cues. They're also attending sign language classes and are probably going to be using sign language with him. They're using a hearing aid and we're doing vocal play which later will lead to speech development and speech activities. We're using every avenue that we possible can to communicate with him. Whatever mode will have meaning for him."

Among the goals for Tyler over the next six months are enhanced communication skills, familiarity with his home surroundings, and the ability to stack toys and eat with a

spoon. Formally outlined in the Smith's Individual Family Service Plan, the goals were formulated and put into writing, as mandated by Act 212, during a lengthy two day meeting last month at the Smith's home. In attendance along with the Smiths were Michele Short, Tyler's case manager from Case Management Offices; William Mitchell, associate director of Case Management Offices; Julie Imig; Barbara Eck; Karen Kyler, a certified occupational therapist at the Barber Center; Kathy Bastow, educational coordinator for the Learning Center at the Barber Center; and Ralph Warner. Similar gatherings, designed to chart Tyler's development, and designate the services he will receive and the agencies responsible for providing those services, will be held every six months until he is 3. Services not available through the Barber Center, including Tyler's evaluation by a specialist in infant deaf-blindness, will be contracted out by the Center and Case Management Offices. Assembling the team



has been a grueling process at best.

"You get so frustrated sometimes," Kristy Smith says. "That's my problem. I want the best for him. We were not going to have a child and not give him the best. I'm a pusher for Tyler. If he's not behind, I definitely don't want him falling behind. The next scary thing is that this child will not speak. I guess there's a little hope in me that Tyler's going to at least be able to talk. That hope is dwindling. As time goes on, I keep trying to think reality. It's not going to happen. Right now, as far as raising Tyler, he's been just like a normal little baby. He has his good moments and his bad moments. We're hoping we're done with the surprises in our life."

According to professionals, the Smiths will have to continue to push for services for their son. "That mother has a great deal of spunk," says Cynthia Ingraham, regional representative for the Helen Keller National Center for Deaf-Blind Youths and Adults in Sands Point, NY, who met the Smith family

at a TASIP (Technical Assistance for Sensory Impaired Programs) weekend for parents of children with dual sensory impairment. "She's a strong woman, to say the least. And she will have to be out there, vocal, fighting for what her child needs."

Ingraham adds, "Sometimes young parents are overlooked. You must be vocal. You don't see many young couples like the Smiths. The husbands frequently can't cope. But Loren is as involved as Kristy, although quieter than she is. That's a commitment."

"The people who make the most noise are the most effective," observes Ralph Warner. "It's a constant battle. The first three years of Tyler's life will be the hardest, fighting for what you are entitled to." Complicating matters, he adds, is the fact that "the laws are brand new this year; providers have not yet learned the law."

The eventual goal is to mainstream Tyler. "If he's got the brains, he can do it," his mother says succinctly. "The school district

will have to pay for an interpreter. A lot of people suggested letting him go down to a school for the blind in Pittsburgh," she says. "I am not one to be able to put a 2 1/2 year old child on a bus at the Millcreek Mall on Sunday afternoons and let them take him to Pittsburgh until Friday. I could not let him go. That is so young. My main goal in life at this point is to have my child mainstreamed."

Area school districts have the resources for such mainstreaming, Julie Imig says. "The Erie School District has classrooms for deaf students. They have classrooms for blind students. If Tyler can't see a teacher signing, then that means he's going to have to have an aide with him signing into his hand."

Loren Smith, who also wants to see his son "get through the normal educational process with as little trouble as he can experience," has another more personal goal for Tyler. "I want to see him develop friends, peers, playmates, buddies," he says. "He shouldn't miss out on that."



But now, still in the early stages of Tyler's development, the Smiths are confident that their son can begin to progress. The decision has been made to stay the course.

"It's almost like this is what I am supposed to do in my life." Kristy Smith says. "You know what I mean? Why am I here? The more I learn about Tyler, the more interested I'm becoming in deaf-blindness. Hopefully, once I get Tyler taken care of and into school, I won't stop. I don't know if I'd end up trying to be an advocate. It's like my whole life now."

"Work, problems, money, taxes, everything - that is so insignificant now. You come home and say, 'Oh my God, what a day I had at work. It's nothing,'" Loren Smith says. "I can come home and look at that little guy, he hasn't got a care in the world," he says, pausing to clear his throat. "He's in his own little world, and he's happy. He's fun. And when I lean down there to play with him, it makes his day."

"This baby is never not going to be happy," Julie Imig observes. "They are so committed. They have a lot of energy, which it takes. They have a lot of intelligence. They're not going to let Tyler's impairments get in the way; they're going to accommodate for it. Maybe Tyler is not going to be president, but he certainly is going to be the best he can be. As productive a member of society as he can be."

### HERE AND THERE

For those who are still able to read large print, THE WORLD AT LARGE is a new large print weekly news magazine which contains stories drawn from such weeklies as TIME and U.S. NEWS AND WORLD REPORT. Available at many New York City newsstands, the publication is also available by mail, \$65 per year or \$37 for a six month subscription. The magazine also includes an enlarged crossword puzzle taken from the Los

Angeles TIMES. For more information, contact THE WORLD AT LARGE, P.O. Box 190330, Brooklyn, New York 11219.

\* \* \* \* \*

The New Ability Brailier is a braille output device known as "soft braille display." It outputs serial data from a computer as a single line of braille text. The product is available by contacting Denistron Corporation, 4325 West Lomita Boulevard, Torrance, California 90505. Tel.: 1-213 530-3530.

\* \* \* \* \*

The Direct Manual Braille Writer, a device for writing braille by hand from left to right, uses a special hollow stylus that presses paper down over a set of pins located in the template openings. The Handicapped Resources Corporation, Inc. wants to furnish



these devices to blind persons and teachers of the blind at minimum cost. For further details, contact: The First American Bank, Braille Writer Fund, 805 East Broadway, Lenoir City, Tennessee 37771.

\* \* \* \* \*

Eschenbach Optik of America offers a new 12-page catalog of illuminated and battery-powered magnifiers and a variety of options. To obtain a copy, contact Eschenbach Optik of America, 25 November Trail, Weston, Connecticut 96883. Tel.: 1-203 227-9490.

\* \* \* \* \*

The Massachusetts Association for the Blind announces its new 1992-1994 catalog for The Store which sells products useful for blind and visually impaired individuals. There are over 175 items in the inventory, including everything from talking clocks and braille

watches, to large-print cookbooks and cookbooks in braille as well as other items. The catalog is available in large print, braille, or on cassette tape. Send \$3.00 for your copy to Massachusetts Association for the Blind, 200 Ivy Street, Brookline, Massachusetts 02146. State your preference for large print, braille, or cassette tape.

\* \* \* \* \*

Dorothy Stiefel, executive director of the Texas Association of Retinitis Pigmentosa, Inc. (TARP), has announced the release of her song (demo) entitled "I Belong to this World," a ballad dedicated to people who are deaf-blind and to all persons with a dual sensory loss. "I really perceive this song as a special gift to be used as a testimonial to share with everyone," she explains, "and especially as an uplifting message for the large population of persons who deal with a dual sensory loss of vision and hearing." For more

information about this special project, please contact Dorothy Stiefel, TARP, P.O. Box 8388, Corpus Christi, TX 78468-0388.

### **A STRANGER**

By Rozelia Rivers

Being along in a strange place  
Is the missing link in a ball and chain,  
Not even a pet to play with.

Being deaf and blind is like being left in a big  
world alone.

If no one tries to communicate with you, it is  
very lonely,

Just a touch will help.

Write or fingerspell your name in my palm.

Say "Hi, my name is Tom, Dick or Harry."

Say anything to break the loneliness and  
isolation.

Oh how I miss my beautiful little pet.

So playful, he seemed to understand what it's



like to be alone.  
He too is alone now.  
It seems that the ones who care and  
understand  
Are always the farthest away.

Please remember, just because we have lost  
our hearing and sight  
We are still human and have feelings.  
We are easily hurt by those we know are  
there,  
Yet for some reason ignore you.

Only God knows those who will too  
join this dark, silent world.

Signed: Lonely Heart

These are the thoughts of Rozelia Rivers from Richmond, VA. Ms. Rivers is deaf and blind and wrote this poem after an incident in her local laundromat where she had tried to reach out to make a friend but her efforts were rejected.





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**NAT-CENT NEWS**

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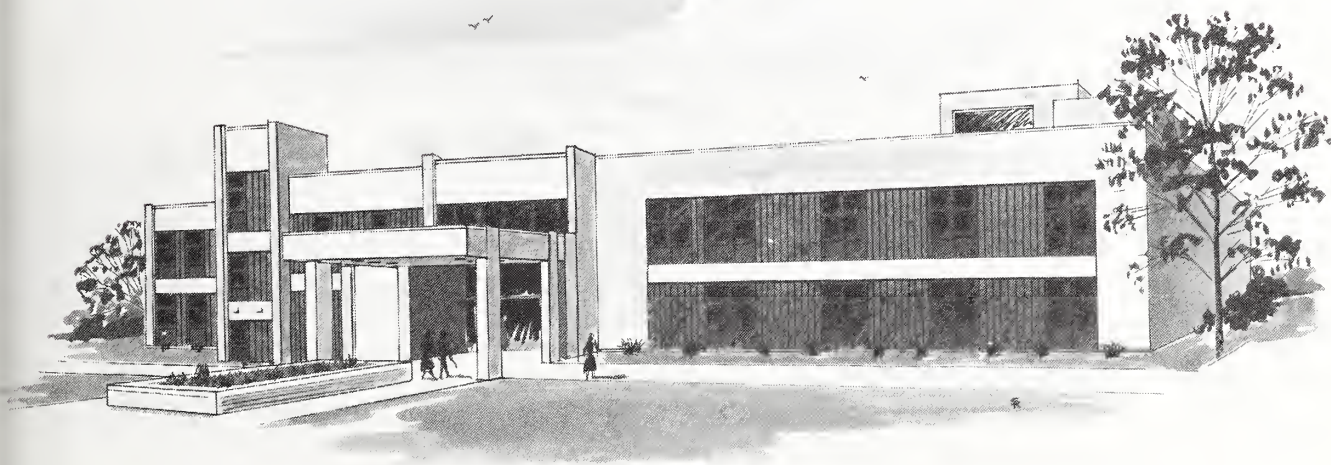
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## **EDITORIAL**

### **RELAYS FOR THE DEAF**

By Robert J. Smithdas, LHD, Litt.D, LHD

Two of the most important recent breakthroughs in technology to assist people who are deaf-blind in their quest for greater independence have been the development of a telephone device, and the establishment of relay systems for people who are deaf. The TeleBraille makes it possible for a deaf-blind user to communicate with anyone who has a telephone device for the deaf (TDD); and the relay systems, provided by telephone companies in various parts of the United States, enable the user to access a wide range of essential and desirable services, and provide direct communication with family and friends.

In the two years since the inception of the New York Relay Service, my wife, Michelle, and I have been able to use the system to contact a wide variety of sources for information and assistance. We have used it

to call plumbers, electricians, and house painters; to order merchandise from mail-order companies; to make arrangements for airline reservations; to make appointments; and to obtain assistance in case of emergencies. I often use it to have groceries delivered to our home, or for occasionally ordering special treats from local restaurants. If we need a number for a specific company, service, or individual, we call a toll-free operator and obtain it from a national directory. Many of our friends who do not own TDD's can contact us by calling a relay service number that will transmit their voice messages.

A man who is deaf-blind in Maryland uses the local relay service effectively. When he needs to see his medical physician, he calls the doctor via relay and makes an appointment. When the appointment is made, he calls the local taxi service, which takes him to his doctor's office.

From personal experience, I believe that all capable individuals who are deaf-blind



should learn to use a telephone device - braille or large print - and be able to access relay services competently. Being able to use relay services efficiently can provide a real sense of security, cut down on frustration in times of need or emergency and increase personal confidence.

Not long ago we had a heating problem in our home. We had turned off the heat because of the extremely warm weather, yet the heat continued to circulate through the house. It required three phone calls via relay and two visits by an expert before the problem was finally solved. But when it was over, it left a feeling of accomplishment - and an increased awareness of the importance of relay services.

## **FIELD NOTES**

By Dennis Brady, Assistant Director, Field  
Services, HKNC

California has been in the news because of earthquakes that occurred near Los Angeles. There will probably be aftershocks for a while because those first quakes were so strong. We hope that the news we have to share with the California deaf-blind community will be more positive.

There are two important things happening. First, we are moving our regional office from San Francisco to Los Angeles; and second, we want to welcome the Lighthouse for the Blind and Visually Impaired in San Francisco as our newest affiliated agency.

Rustie Rothstein, regional representative for HKNC's Southwestern Region, is relocating her office to Los Angeles. Rustie will be letting people who are deaf-blind throughout her region know that she has moved. As of August 14, 1992, her new address will be:

Helen Keller National Center  
Southwestern Region  
6851 Lennox Avenue  
Van Nuys, CA 91405-4097  
(818) 782-9935  
(818) 782-9936 (TTY)

The new office in Los Angeles is in an accessible building, and there is a convenient meeting room on the first floor that can be used by people who are deaf-blind. Rustie will still be travelling through California, Arizona, Nevada, Hawaii, Guam, Samoa, and the Trust Territories.

The second important announcement is that the San Francisco Lighthouse for the Blind and Visually Impaired was selected as an affiliated agency in July. The Lighthouse has been serving people who are deaf-blind since the 1950's through many of its programs. Since the early 1970's, many deaf-blind people have participated in the Lighthouse's social and recreational activities. By affiliating with HKNC, the Lighthouse hopes to make more of its services available



to the deaf-blind community. It hopes to provide services throughout the northern California area. The San Francisco Lighthouse is currently looking for a specialist to work with the deaf-blind community.

We are pleased to welcome this agency as HKNC's 36th affiliate, and we are confident that they will make a big difference in services for the northern part of California.

### **SPECIAL NOTICE**

In the last issue of NAT-CENT NEWS (May, 1992) we announced the upcoming conference, "Challenge to Independence", to be held in Dallas, Texas, in November. We regret that an error was made in giving the dates of the conference. The correct dates are November 5-7, 1992.

This conference has already generated considerable interest, and we anticipate that it will be a successful, informative meeting for everyone. For more information, contact

Martha Bagley, Helen Keller National Center,  
4455 LBJ Freeway, LB#3, Suite 517, Dallas  
TX 75244-5998. Tel.: (214) 490-9677 voice  
and TTY.

**RENTON MAN'S RECIPE FOR SUCCESS**  
**IS CAJUN RESTAURANT**

By Geordie Wilson

(Reprinted with permission of The Seattle  
Times, Seattle, WA)

For Danny Delcambre, the world is silent and fuzzy around the edges - but full of flavors. The Cajun-born man's flavors of choice run to the savory spices of his native Louisiana. The simmered strains of French, Caribbean, Spanish, African and American foods make up the cuisine that runs in his blood like a birthright, learned first at his mother's side.

Those are the flavors Delcambre dreams of unleashing as a chef in his own Seattle area restaurant. Now a Renton resident, he went back to New Orleans this winter - back to the

Mecca of Cajun cooking for a 10-week internship in the kitchen of K-Paul's, one of the city's most famous restaurants.



Chef Paul Prudhomme (L), and Danny Delcambre (R) at K-Paul's in New Orleans.

But there's another birthright running in Delcambre's blood, one that makes his restaurant odyssey all the more remarkable. Delcambre was born with Usher syndrome, a hereditary disorder that caused him to be deaf and legally blind.

The disorder is disproportionately common in parts of Louisiana, said Elizabeth



Hadden, a doctoral candidate at Tulane University Medical School. She said the region's historical isolation and low population created a gene pool susceptible to hereditary disorders.

Delcambre, 32, has severe tunnel vision and night blindness; he has trouble seeing contrasts and stairs are a challenge. He can read and write large type, but he communicates mostly through American Sign Language. He does not speak.

Delcambre worked in a Louisiana food warehouse until the oil bust there in the early '80's took his job away. He moved to the Seattle area in 1987 because of its supportive deaf-blind community, and worked for two years in a machine shop for blind workers. But when it became clear he would have trouble getting a full-time job in a machine shop as a deaf-blind worker, Delcambre shifted his goals.

"I started to focus in more on what I really wanted to do for a career," explained Delcambre, in writing. He was taking classes

at South Seattle Community College and eating regularly in the dining hall where food was supplied by students in the culinary arts program. "That got me thinking about how much I like cooking Cajun, and why not become a chef?"

Why not indeed?

Delcambre has since taken four quarters of cooking classes at Seattle Central Community College, which provides interpreters. He's now finishing up his studies there with an independent project to set up a business plan for his restaurant. He has hired a restaurant consultant, is lining up loans and is looking for a good location. He hopes soon to open "Delcambre's Ragin' Cajun," which he estimates will cost between \$30,000 and \$50,000.

At the start, Delcambre envisions a small restaurant, about 10 tables, serving lunches only. Kitchen workers would have to be able to sign fluently, he said. "The menu would have to be limited - I can't have an extensive menu like they do at K-Paul's. That would be

way too much work," said Delcambre through an interpreter.



Danny Delcambre hard at work with the tools of his trade.

Usher syndrome presents Delcambre with unusual challenges in a kitchen, but it doesn't keep him from doing anything, he said. At K-Paul's, for example, he worked on almost every stage of food preparation: cutting vegetables, making sandwiches, deep-frying seafood, making sauces and salad dressings and baking breads.

Because of his deafness, he carries a special timing device that vibrates to signal when something is done cooking. Because of



his limited sight, he has to be careful to put ingredients where he can easily find them. "That is one thing that is a problem in a big kitchen because nobody puts things away. That wastes a lot of my time," Delcambre said.

But for a chef, sight and sound are secondary senses. Taste and smell rule in a kitchen and there Delcambre is at no disadvantage. "It seems to me that people with good vision don't use their sense of smell as much as blind people do," Delcambre said. He suggested an experiment for those with full vision. Put a blindfold on the next time you make coffee, Delcambre said, and see how it comes alive.

At K-Paul's, Delcambre said he learned a few restaurant tricks and refined his all-important sense of taste. "I learned that it's important to always taste in every step of a procedure. You can't just rely on a recipe and expect the food to taste the same, which is what a restaurant needs. Ingredients change so you can't rely on the flavors to stay

the same. A good chef has to be able to adjust flavors while cooking."

Delcambre said support for his venture has been strong among his friends and in the deaf-blind community. His wife, Holly, said opening a restaurant will be a good match of his interests and abilities. "What was important for me was that Danny do what he wanted to and not that he listen to what other people told him," she said.

### **WHAT'S NEW AT HKNC?? THE P.F.P.**

By John Mascia, Coordinator of  
Audiological Services, and Valerie Chmela,  
Work Experience Department

The introduction of Personal Futures Planning (P.F.P.) represents a change in attitude at the Helen Keller National Center. P.F.P. is a technique that provides the occasion for people to clarify a vision for the future of our students who are deaf-blind; it is a tool that can help people implement

ideals of person-centered development. The goal of P.F.P. is not only to help our students plan for the future, but it also represents a different way of seeing and thinking about people who are deaf-blind. According to Beth Mount, the creator of the P.F.P., the process challenges those involved to 1) find and develop the gifts of each person, 2) develop a vision that expresses these gifts 3) build a support group to make these ideals happen, 4) build a community network of acceptance, and 5) change services to be more responsive to the interests of people. The decisions made during a P.F.P. meeting are made by the student, family and friends. In the past, most of the decisions regarding a student's future were made by the professional.

The first step in developing a P.F.P. for a student is to assemble a group of people who are committed to securing the best possible future for the student. The members of the "team" may include the following people:

1. Student



2. Members of the community (Pastor, friends of family, etc.)
3. Family (parents, aunts, uncles, etc.)
4. People from school (teachers, fellow students, etc.)
5. Service providers (job coach, doctor, etc.)

The P.F.P. process is broken up into two distinct parts. The first part is the personal profile and the second part is the plan itself.

Ms. Mount notes that the personal profile provides an opportunity for the facilitator, the person who will be the focus of the plan, and invited friends and guests to create an overview description of the current life of the person. She states further that the personal profile can help the facilitator and others:

1. Get to know the person and listen to them.
2. Develop a shared appreciation of the gifts and capacities of this person, as well as the barriers and struggles they face.
3. Value and include the perspectives of

family members, direct service workers, friends and other people who may often be excluded from a planning process.

4. Strengthen the voice of the person by clarifying their interests and desires, and naming the things that prevent them from expressing their capacities.
5. Establish a record of how things are now for future reflection.
6. Translate human service jargon by finding a common language.
7. Discuss values, options and feelings in an informal meeting.

The facilitator, or group leader, will help focus the group by utilizing a specific frame work or map during each profile meeting. A map is a color-coded representation of the information gathered that is displayed so each group member can follow along. The maps used are as follows:

1. Relationship Map: Identifies opportunities for personal support and assistance. This map helps to illustrate

the most important people in the focus persons life.

2. Places Map: Describes the pattern of current daily life. This map helps to illustrate how the focus person spends his/her time.
3. Background Map: Provides an overview of the life experience of the person and family. The background map helps to illustrate positive experiences from the past to build on. It allows for appreciation of the traumas, loss and grief in life.
4. Preferences Map: Describes personal preferences, gifts and interests as well as conditions to avoid.
5. Dream Map: Describes ideas about personal dreams and desires for the future. Describes how people feel about the opportunities and obstacles they see to making things happen.

Other maps can be invented by the facilitator to help the "team" understand life as it is experienced through the eyes of the



focus person.

According to Ms. Mount, the planning meeting provides the opportunity for a group of people to develop a powerful, positive future that inspires a person to work hard over time to implement this vision.

An effective future plan will reflect several categories for development: home, home ownership, home making, work, transition to work, work experience, school, friends, fun, community life, family life, communication, etc. The choice of categories will reflect the interest of the person and life stage.

The P.F.P. process has proved invaluable in helping HKNC to continue to improve the quality of life for people who are deaf-blind. It encourages empowerment of individuals to achieve their preferred life style in the community with the highest level of desired independence.

By utilizing the P.F.P. format, HKNC is re-affirming its commitment to respect the right of each student and their family to take an active role in making decisions for the

future. We respect the differences among people and, therefore, realize that programs must be individualized to meet the needs of each student.

In conclusion, the P.F.P. process fosters person-centered development. A group of people who are committed to securing the best possible future for the student have meetings on behalf of that student. The mapping procedure illustrates through graphics the strengths, likes, dislikes and dreams of the focus person. The goal of this process is to help the student dream about his/her future and offer assistance in making the dream (or at least a piece of it) come true.

### **WORTHY OF PRAISE**

Rajinder Singh Sethi is 34 years old and lives in Bombay, India. He is totally blind and has had a very severe hearing loss since early childhood.

But last year - 1991 - one of his dreams came true: to successfully complete his doctorate at the University of Bombay, with a thesis on the "Socio/Educational Problems Of Employed Blind Persons In Bombay." He had previously received a degree in sociology, and had successfully completed a master's degree in history.

Rajinder, who has attended a convention of the American Association of the Deaf-Blind, is an active member of the Standing Committee On Activities of Deaf-Blind People of the World Blind Union, a world-wide organization of blind people from many nations. Sensitive and intelligent, when he was ten years old authorities wanted to exclude him from school because they figured he was mentally handicapped, probably due to his dual disability.

However, a teacher, Rehmurt Fazelbhoy, believed in Rajinder, as Ann Sullivan believed in Helen Keller, and provided him with the basic education which enabled him to reach high levels of intellectual activity.



Now Rajinder would like continue his research and dedicate himself to a permanent job.

## **INDEPENDENCE DAY FOR KELLER** **GRAD**

By Christina Cronin Southard  
(reprinted with permission of the Port  
Washington News, Port Washington, NY)

"If I can do it, anyone can," assures Linda Carter.

Linda Carter is full of optimism after a twenty month training program at the Helen Keller National Center (HKNC) in Sands Point. She completed her training at the Center in July and, for the first time in her 30 years of life, she is living independently with her daughter, Meagan, age 6.

Carter hasn't had an easy go of it. She was born hard of hearing and didn't speak until she was fitted with hearing aids nine years later. She was mainstreamed through school

in Florida until high school. Although she couldn't hear her teachers, it was not until she was told that she was not prepared for graduation that her lack of basic education became uncomfortably apparent to her. To compound her difficulties, in her early teen years she started having problems seeing in the dark and her peripheral vision started to fade. Doctors told her that complete loss of vision was a future probability.

Her family accepted her limitations. She managed to work at the family's restaurant, although she testifies that she was a terrible waitress. "Since I had no peripheral vision below my waist, I was constantly tripping over things. The other waitresses were warned to stay away from me," she laughs.

When she was 24, she married and Meagan came along. Life seemed pretty fair until she went to a Fort Meyers eye center for a check up. The examiner informed her she had retinitis pigmentosa. He also informed the Bureau of Motor Vehicles and her license was promptly revoked. Second opinions all

concurred with the original diagnosis. Total blindness could strike at any time with little warning.

In early 1990, while visiting her brother in Livingston, New Jersey, Carter went for an eye check-up. The ophthalmologist recommended the Helen Keller National Center for personal adjustment training. In October 1990, she came to the Center. Even though there were many new skills she had to learn, she was relieved but frightened. Many of her classmates spoke solely in sign language. "Everyone was friendly, but I had no way of communicating with them," said Carter.

Although the training was rigorous and demanding, Linda took the time to appreciate the local weather conditions. "I saw snow for the first time and I let it touch my face," said the native Floridian. For the first time, she basked in the changing seasons. She missed her daughter terribly but knew her time spent at HKNC was part of a bigger picture for mother as well as daughter. At HKNC,



Linda Carter had new challenges but she also had to meet some old ghosts. Due to the fact that she was pushed along in school because



Linda Carter (left) is pictured at a going away party in her honor with Joseph McNulty, (center) HKNC Director, and her daughter Meagan (right).

of her hearing impairment and missed about 70 percent of what her teachers were saying, Linda now had to face her own reality about literacy. She has worked hard to increase her reading level and she works with a volunteer to make the passage a little easier. A curriculum of sign language, braille, home management skills and cooking has made Carter

ready for living a self-supporting life.

Her interest in horticulture landed her a job

with Dan Murray Garden Center on Shore Road and later a position with a florist on Port Washington Blvd.

Mother and daughter were chosen as poster models for the 1992 national Helen Keller Deaf-Blind Awareness campaign.

Linda is very optimistic about their future. At the time of the interview, she was needlepointing a piece for their next home. "Bless This House," it read.

## **THE POWER OF SCENT**

By Therese Rose Kokis, Volunteer, HKNC  
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A Cosmetic/Aromatherapy program began in August 1991 at the Helen Keller National Center. The question posed: can scents be a motivating factor to encourage daily living skills? The overwhelming response was yes. Definitely! Given a choice between a scented product, or an unscented product the students consistently chose the scented one.

For example, many of our student's hands were chapped and dry. Students enjoyed the scent of the hand cream and applied the cream and rubbed it into their skin. What was found to be truly remarkable was that these students would not normally perform daily living skills had it not been for the scent of the products which they found so pleasant and stimulating. Another interesting finding was that students judged the effectiveness of hand and body lotions based on the scent of the product alone. Many students loved the body cream by Karl Lagerfeld-KL. They found the soothing fragrance of the product so appealing they were convinced this product could moisturize the skin and make it supple, once again based solely on the fragrance.

Our students show a definite preference for the scent and texture of the products they use - a light scented product with a non-greasy, non-sticky texture. Students did not like the scent of strong perfumes. A beneficial hand cream our students enjoyed was Vitamin A,D,E, sold by The General Nutrition



Centers (GNC). These products are available nationwide and cost only a few dollars.

Scent has proven to help orient blind individuals in their homes. Laura Rocchio, assistant residence director at HKNC, made a wonderful discovery. Air fresheners or potpourri sachets can be hooked on to a door at eye level to orient individuals to their whereabouts. An excellent product is "Little Tree Air Freshener". This product is made in the U.S.A. by Car-Freshener Corp., Watertown, N.Y. 13601-0719. In my experiments, I have found this product to be superior as it retains a potent fragrance for a long period. It is also cost effective at fifty cents to one dollar per air freshener.

An example of how this product can be utilized is to place a vanilla air freshener on the kitchen door or a peach air freshener on the bedroom door. As one walks by, the scent can designate areas and thus reduce confusion - an aromatic way to orient and reassure.

It is said that beauty cannot be bought in

a bottle. However motivation can. Scents can be stimulating, motivating and enhance personal grooming and skin care. Scents can have a tranquillizing effect during periods of agitation. Several students were very restless, rocking back and forth and having difficulty focusing attention. The students smelled the potpourri and had a fragrance applied to them. This produced a sense of calm and aided the students to focus and increase their attention span.

Scents can be an essential aid in behavior modification. During the Cosmetic/Aromatherapy program scents have had a calming effect on many students and have helped to promote more socially acceptable behavior. One student tended to rock wildly back and forth and call out. Scents had a very soothing effect on this student and her restless behavior became more contained.

Scents increase socialization during Cosmetic Therapy. Students are enthusiastic and the women love having make-up applied

to them or applying it themselves. There is an increase in communication both verbally and using sign language. Scents have shown themselves to be psychologically uplifting. Many times when students are depressed they do not groom themselves. A little pampering does a lot for ones self esteem.

The Cosmetic/Aromatherapy is applicable for people who are deaf-blind, mentally retarded, visually and hearing impaired - all ages - and particularly the aged. This program can be used as a motivating factor in daily living skills for the physically and emotionally challenged. Scents can be used as an effective therapeutic aid. Scents have proven to be a "helping hand", a motivating factor for people with special needs.

## **HERE AND THERE**

Red Lobster, a national seafood restaurant chain, has offered braille menus since the 1970's. It is now offering its menus in a



"magnified" large-print format for visually impaired diners.

\* \* \* \* \*

American Greetings Corporation has announced that it is expanding its line of greeting cards for the visually impaired. The company noted that an increasing number of older Americans are losing their sight, hence the reason for expansion. American Greetings currently offers large-print birthday, sympathy, and get well cards. It will expand its line to include a variety of holiday cards.

\* \* \* \* \*

Braille greeting cards, uniquely designed and with braille messages for holidays, birthdays and all occasions are available through the mail.

For information concerning prices, contact: Braille Greeting Cards, P.O. Box 849, Round Pond, Maine 04564.

\* \* \* \* \*

Safe-t-Lite is a new cane with a built-in xenon strobe light. When switched on, the xenon strobe illuminates the entire length of the cane and can be seen half a mile away. The cane can be ordered in various lengths to suit the user. The bright, intense light of the cane may be of value to individuals who have night blindness, and as an added safety precaution for blind and visually impaired travellers. The cane sells for \$65.00.

For further information concerning the cane, or to place an order, write to: Grant Foster, 4120 Dalmar Avenue, Victoria, British Columbia, Canada; telephone: 1-604-479-1350

\* \* \* \* \*

Lock-r-Lock is a new push-button lock that requires no key. The buttons are easily felt and have a positive action. Each padloc has a four-digit combination that is easy to use.

Further information is available from: Hilltop Associates, Customer Service, P.O. Box 273, Grinnell, Iowa 50112; telephone: 1-515-237-6828.

\* \* \* \* \*

NAT-CENT NEWS in no way recommends or supports the items mentioned above; they are included as special items which may be of interest to consumers who are deaf-blind.

### **DEAF-BLIND WOMAN IS CREATIVE**

by Cynthia Ingraham, HKNC Regional Representative, East Central Region

In a suburban location just outside the Richmond city limits, and just outside the line of public transportation, Valerie Luther creates a tool for relaxing and releasing frustration. Mrs. Luther, who is the mother of three, has been experiencing difficulty securing employment as the result of the remote location of her residence and employers reluctance to hire someone with vision and hearing impairments. As a means of filling the voids in her life created by lack of employment opportunities, Mrs. Luther sits and creates magic and amusement.



The most recent creation has proven to be a great tool for releasing penned up anger. The Dammit Dammit Doll is great for those days when the hassles of the job or life have gotten your dander up. Just take the legs of the doll, find a sturdy surface and pound away. While doing this, say "Dammit Dammit." It works wonders. For children there is a smaller version of the Dammit Dammit Doll called a No No Doll, for when a child is feeling mad. They can learn to take their frustrations out by slamming and shouting "No No" instead of throwing their toys. (These toys are childproof).

In addition to the tension relieving Dammit Dammit Dolls, Mrs. Luther also makes beautiful Mop Angels and Mop Dolls for all occasions. So,



Valerie Luther and friends

for those of you out there that are looking to release a little anger, or to add some beauty to your home, why not contact Mrs. Luther and invest in a Dammit Dammit Doll or a decorative Mop Doll or Mop Angel? Her address and phone number are: 8612 Peach Grove Road, Richmond, VA, 23237 (804)271-3531.

## **HOW I COPE WITH DEAFNESS & BLINDNESS**

By Anthony H. Murphy

Look, listen or read or what ever you wanna do. I'm 16 years old, and live in Pittsburgh. The school I attend is John A. Brashear High. I'm going to tell you a little about myself.

I was born on December 10th, 1975. When I was very young, about ten or twelve months old, I was walking and talking like a jungle monkey. I was so active that I played many a wild game with the coffee table, chair

and couch of my great-grandma's house. Now remember, I told you I was very active.

The coffee table, the chairs and the sofa were my favorite things in that house. I loved to jump from one to the other. I'd jump from the sofa to the coffee table to the chair on the other side of the room. I'd done this so many times, and I'd mastered it to the point where I could jump through all three of these things. Now, I decided it was time to skip the table, and jump from the sofa to chair. Well, I made it the first time. The last time I did it was really going to be the last time.

The last time I jumped from the sofa to the chair, skipping the table, I fell and hit my right eye on a sharp corner of the table. There was a long gash on my right eye, and it stretched from the cheekbone to just above the eyebrow. I went to the hospital and, after a few months, the scar wouldn't heal. It wouldn't scab or nothing.

When I was taken back to the hospital, they did a series of tests to see what was the



matter. After all the tests, they told my mom I had retina blastoma. This is cancer of the eye and, if not treated soon enough, can spread to your whole nervous system. I was in and out of the hospital for six months. During that period of time, I lost my sight and my hearing. Hearing came later.

After all the trouble with the hospital, I was finally left in peace at home. I couldn't be in kindergarten, not public anyway. My mom had to think about where to send me to school. Finally, she settled on Western Pennsylvania School for Blind Children (WPSBC). I was two and a half or three when I was enrolled some time in 1978. I didn't like the school at all when I first started there. To me, it was very spooky, plus, with mentally handicapped people down the hall ready to explode any minute, I was scared I'd get hurt by one of them.

While I was at the School for the Blind, I was taught how to cope with my blindness by reading braille and learning many different skills to help me out in life. During this time,

I'd also lost my hearing, so I started having communications therapy.

At first, I didn't wear hearing aids, because I still had quite a lot of hearing left. I was still able to hear on a regular basis. It was when I was between the ages of three and six, that I started to wear hearing aids.

The people at the School for the Blind here in Pittsburgh, had a communication therapist come and do testing on my hearing. My first audiology appointment was "TERRIBLE!" or so I'm told. I would laugh at the most unobvious things when I should've been raising my hands for the beepers. Or, I just totally ignored them altogether. My second appointment, I did better, but my hearing was bad. They recommended one hearing aid for me. Then, a few years later when I was seven, I was told to wear two. And, ever since, I've been wearing two.

Coping with blindness and hearing losses were very hard for me. I was a bad kid. I'd fight for things that other kids had first, or just be very naughty and ignore the teachers.

But I learned, and I found that life can be very entertaining.

After seven years in WPSBC, I was pretty much on the way to recuperation, I guess you could say. I'd learned mobility and was ready to go outside of the school. But, when I was first taught mobility, it was hard because there were so many rules to remember. The cane was introduced to me, and I thought that the cane was for hitting with. You know, to fence with. I thought we were going to be taught how to fight. But, NO! I was told it was a traveling tool. With the cane, I learned how to cross streets, go places and catch buses in the Pittsburgh area. The best cane for me was a folding, six-piece aluminum cane.

WPSBC was a good school after that, and I was proud to be there. But, I was told that I might be going to public school and you know, if you've been in special education school, you can understand my confusions as to what public school was. It was explained to me. When I was told, I started thinking, this is it! This is where I'm going to be for



the rest of my life! The real world!

I was a bit nervous about leaving. Many people had told that, unlike WPSBC, public school was real. There were going to be ignorant people who wouldn't want to help me, and would laugh at me every chance they got. Well, some of it was true. I was to attend Reizenstein Middle School here in Pittsburgh. I'd be starting the seventh grade. I attended it, and I found it quite exciting. There were many things to do there like medical careers' program, cooking, sewing, music and art. It was just wonderful!

When I got to eighth grade, I joined a program called JIF. This stood for Job Information Fundamental. We applied for the program in hopes of getting jobs. You attend teaching sessions and you were lectured and taught about what you should do, and how to go about getting a job. It was fun and I got a job at VRC (Vocational Rehabilitation Center). You got paid for it, too.

Now, as I wrap this up I am at Brashear

High School. I find this school very particular. It's very crazy here, but fun all the way. Brashear is a good school, but it's humongous! It doesn't worry me at all, though.



Jim Gallegan (left), resource instructor for Vision Classroom at Brashear High School, and Anthony Murphy (right) work on an assignment together.

So you see, being deaf-blind shouldn't put a damper on things. There are ways to cope with that. I have some friends, and they understand me and what I go through. Not only me, but many of you other deaf-blind

people shouldn't give up hope on life just because of your impairment. And, you know something, I don't consider any one of us impaired, handicapped or none of that. We just have to prove to the world that we're worth something, too, in the general public.

## **ANIMALS AS HEALERS AND FRIENDS**

by Michael Honan, Instructor in LIFE  
Program, HKNC

The people that I work with are deaf-blind, developmentally disabled, and possess limited life experiences. It is often difficult to find pleasurable as well as therapeutic leisure activities for them. To add to this challenge, these individuals have little or no formal communication skills, which leaves the teacher with a limited functional response. The majority of these students use behavior as a means of communication. There are currently five students in the Living Innovations in a Functional Environment Program (LIFE) at



the Helen Keller National Center who interact with the animals.

There has been research done with animals and their interactions with humans who have various ailments. All of the studies had the participants interact with animals for different periods of time. A study was conducted by New York college students in which they visited a home for emotionally disturbed children. The team brought with them a cat and a dog to interact with the children. This particular study lasted for eight weeks. The results showed that the children were acting out less often than when the experiment began. It must be understood that dogs don't work miracles and can't fix everything (Burke 1992). Animal companionship is beneficial because it is uncomplicated, unlike human interaction. A second study was done with physically aggressive patients. The results found the patients to be more tolerant of people standing next to them when an animal was present.

Animals are nonjudgemental. They don't talk back, criticize or give orders. They give people something to be responsible for and offer a nonthreatening outlet for physical contact. It has also been discovered that animals not only have a psychological effect but also a physiological effect as well. Such effects are lower heart rate, calmness and stress reduction.

There are several goals that I hope to accomplish by involving the students in LIFE with animals. They are as follows: socialization, reduction of self-injurious and/or aggressive behaviors, developing feelings of attachment and companionship, eliciting positive responses to unconditional affection and anticipation of return visits. This type of therapy has been adopted by numerous institutions, such as nursing homes, jails and hospitals.

Nora Sepler, a volunteer from the North Shore Animal League, visits us monthly with her two puppies. She has come to the Center twice as of this time. Some of the students

had an extremely positive response to unconditional affection, and exhibited a strong sense of companionship. None of the students became upset while the animals were present and the students socialized with each other.



**Curtis Moir (L) and David Mills (R) enjoy two of the puppies.**



**Milton Thomas and friend relax together.**



**Nora Sepler (L), from the North Shore Animal League shows Curtis Moir (R) how to attach a leash.**



After seeing the effect that the animals had on some of the students, it was decided that I would bring in my own dog on a weekly basis. This will make the program more consistent which, in turn, should bring an even more favorable outcome.

## **THE MAKING OF AN ADVOCATE**

By Mary Johnstone

(Reprinted with permission of Gallaudet  
Today)

Tucked in the southeastern corner of Wisconsin, the city and county of Kenosha hardly have the centrality necessary to play a dominant role in shaping the state's society. Yet one woman made it a hub of activity, awakening the rest of Wisconsin to the special needs of its deaf and deaf-blind citizens.

That was not exactly what Edith Christensen set out to do as a young girl growing up in Kenosha's neighboring Racine County. She wanted a career in nursing. But

nursing was not to be a part of her future.

Most of her life before and after her marriage in 1944 to Robert Simons, who is also deaf, would be a struggle to retain as much hearing and sight as possible. Now, profoundly deaf and legally blind, Edith Simons has gained widespread acclaim as an advocate on behalf of both the deaf and deaf-blind populations.

When Simons first became involved in advocacy, there was almost nothing in the state of Wisconsin's statutes that regulated services for deaf people. That was 16 years ago - deaf people had only then won their right to drive cars and were fighting for fair insurance costs for deaf drivers. "What did exist," she says, "was a rarity much envied by deaf people in many states - a small private State Service Bureau for the Deaf, a one-person, part time operation that was funded by the state government. Other than that," she adds, "zilch!"

Today, the picture has changed. The energy required to keep pace with Simons as

she dashes from committee to council to legislative assembly would discourage all but the most zealous campaigner. She advocates on the local, state and national levels. The proliferation of services and advocacy during the years between 1975 and 1992 are largely attributable to Simons' dynamic and forceful crusade to make a difference in the lives of people with disabilities, especially those disabilities that she herself has known so long and intimately.

When asked, Simons will say that she began her advocacy work in 1975 when she was asked to be on the first Governor's Committee on People with Disabilities, a position she held until 1985. However, her role is rooted in a youth that included disabilities born of the usual diseases affecting children of the times and then some.

Growing up during the pre-World War II years, Simons recalls that during her early schooling she seemed to catch all the contagious diseases going around to an extraordinarily severe degree. "Measles was



very severe, and I think that is what started my hearing loss," she says. In fourth grade, she contracted scarlet fever. Shortly afterward, her sight began to deteriorate rapidly but stopped short of blindness. "I was very nearsighted, but my vision was clear within a limited range, so I was able to keep up with my schoolwork," says Simons.

At age 17, while still a junior in high school, Simons was diagnosed as having progressive hearing loss. "That was a disaster from day one," she says. "Looking back, I was hard of hearing and 'hard of seeing', but together they paralyzed me. But today I think, 'How much I had.' I quit school for a year, but my wonderful dad persuaded me to go back and graduate."

When Simons graduated from high school in 1939, she sought help from the newly formed Department of Vocational Rehabilitation (DVR) to attend college. "The DVR counselor assigned to me was wonderful and wanted to help me, but he did not have much experience and there was little money.

I was given aptitude tests that showed I could do college work. But the counselor's question was, 'How will you hear the professors?' I was too young and uninformed at the time to fight it," she recalls. "But that was the old me, not the me that people have to contend with now."

Instead of college, Simons enrolled in a short-term training program in physical therapy. Soon after finishing, she met her future husband at a Halloween party at the Milwaukee Hearing Society. "I knew beans about deafness other than my own," she says. "Bob did not speak, only signed, and I knew no sign language - communication between us was really limited. We wrote notes at first, and I learned the manual alphabet." Soon she was learning to sign.

"Marrying Bob," says Simons, "I married into the deaf world - a whole new world living side by side with the hearing world, yet absolutely invisible." As time went on, the deaf people found that her English was good, and they came to her with letters that needed

clarifying, business papers to fill out, or for help with situations they did not know how to handle. "Deaf people learned that they could trust me," she says. "But I had to tread a fine line, not giving advice, instead steering them to the right agency or right person for help. I also tried to give them the feeling that they did not have to accept anything they did not understand or do anything they did not want to do. I was often asked to go along with a deaf person and help with a complex situation.

"Becoming hard of hearing was hell. I still felt like a hearing person, but I did not fit into the hearing world anymore. Every encounter was torture. I was robbed of self-confidence and just wasn't me anymore. But, when I became familiar with the deaf world, I was appalled at the many injustices imposed on them. Deaf people were subjected to the same ills of the general society but had no access to the remedies. My problems paled in the face of their reality - a good lesson."

The many victimizations of deaf people



became apparent to Simons at her first job with the Racine Center for Independent Living (CIL). Helping in those social areas of deafness was not in her job description, she says, but "the deaf people put it there, and they flocked to the CIL because there was no other place to go, and they knew me from years back and trusted me. The responsibility was both scary and wonderful."

"The very nature of deafness forces uncertainty on people. It's hard to know what's going on, and people tend to stay out of things, where it is safer," she says. "But, timid and scared, I put myself on the road to advocacy."

Then, in 1977, when not one eligible deaf person offered to serve as president of the Wisconsin Association of the Deaf (WAD), Leo Dicker, a hearing professor at the University of Wisconsin at Milwaukee, stepped in and took the post. When WAD's first legislative committee was formed, Simons was asked to chair it. "I didn't know how," she says. "I sort of learned on the job." Since

then, each president of WAD has asked Simons to stay on as its legislative chairwoman.

Among Simons' early involvements was service on the Board of Directors for the American Association of the Deaf-Blind from 1975 to 1981, "for the six turbulent, formative years, wrestling out our identity, goals and a constitution for a viable, growing organization." Simons received the 1978 Kenosha Woman of the Year award for improving the conditions of deaf, deaf-blind and people with other disabilities - the first of many such awards. She has just finished 12 years as chairwoman of the Wisconsin Association of the Deaf/Registry of Interpreters for the Deaf Joint Legislative Committee (WAD/RID JLC), but will remain involved in its activities until a new chairperson is installed and this year's agenda is carried through.

Simons is also on the Boards of Directors for a center for independent living in Racine, Wisconsin; the Wisconsin Statutory Council of

the Hearing Impaired; and the state's new Telecommunications Relay Systems (TRS) Council, and is a member of the Wisconsin Alliance for the Deaf, Deaf-Blind, and Hard of Hearing.

She has served in widely diversified capacities, from delegate to the White House Conference for Handicapped People in 1977, to representing the United States, along with five other deaf-blind people, at the 1989 Helen Keller World Conference on Deaf Blindness held in Stockholm, Sweden. One appointment, which she regrets having had to decline for personal reasons, was membership on the Kenosha County Public Welfare Board. She was the first deaf or disabled person to be asked to serve on a board or commission in the history of that county.

But it's one thing to set up committees and attend meetings and another to take charge, establish appropriate contacts in government and get practical results. And results is what Simon gets, as in founding an agency in Kenosha 12 years ago to provide a



limited service telephone relay service despite formidable opposition from the state telephone company, and getting private and county funding for it. That relay service was maintained until 1988, when a new statewide Telecommunications Relay Service was initiated.

The new relay service was accomplished after WAD's legislative committee, chaired by Simons, sat down with telephone industry representatives and hammered out a mutually satisfactory bill. "It would have been a landmark law," says Simons, "but instead of a law, it was passed as a governor's executive order, which took away the Joint Legislative Committee board's power to operate the new full-time relay service, leaving it functioning only as an advisory body." Another project recently accomplished was getting the Kenosha County government to buy and install equipment for a 911 TDD emergency line.

Other important JLS proposals that recently passed in the legislature provide for

American Sign Language to be taught as a foreign language alternative in Wisconsin public schools; for TDDs and visible fire alarms to be placed in hotels and motels; and an expanded bill to provide interpreters for emergency situations. Left over from last year's session is a JLC proposal for a state funded interpreter service for court sessions. "I am known for my deep regard for interpreters and for saying that 'interpreters come from heaven' - they have so much on the ball themselves, yet they are willing to take a subsidiary role to help others," she says.

As chairwoman for a TDD committee sponsored by the Kiwanis Club and the Quota Club, Simons helped put TDDs in hospitals, libraries, fire stations and more than 105 homes. Ultratec, a leading TDD manufacturer, "liked what we were doing," she says, "and they offered to work with us. We bought TDDs from them at a lower cost and passed them on to deaf people at the same cost, in easy payments whenever necessary."

Simons emphasizes that, although she did a lot of things as an advocate, she did not do it alone. "Many of those things were the result of many people working together - not just me. What I am good at is starting things. I am a risk-taker, a doer. That is not to say that everything I did worked, or that everything I did was right," she adds. "I did make mistakes."

With all the gain, Simons explains, "much of our advocacy and committee work consists of maintaining and hanging on to what we have accomplished. There are always funding cuts to battle and political factors to deal with. We must constantly be on guard against having our services whittled away."

Simons points out that "any bill faces a perilous journey through the legislature. There are any number factors that may affect it that we can't control. You've got to have friends in the legislature who will support it." As an example, Simons credits State Assembly Majority Leader James Wahner, who chaired the Governor's Committee on Problems of



Deaf People, and State Senator John Maurer, who was a committee member, for winning legislation mandating a Bureau for the Hearing Impaired.

To gain recognition of the need for the bureau, Simons coordinated an effort to get deaf people to rally at the state capital. She did this while attending Gallaudet University in 1979 as a special student for one semester carrying 19 credits. "Two hundred deaf people and interpreters were very visible in the gallery of the state assembly that day and we were later told that is what helped us," says Simons. "I can't forget the dedication and determination of those two men."

Before the current legislative session are two bills that Simons calls her "babies." One would provide people who are deaf-blind with TDDs and related braille equipment to access the telephone system, and the other would establish a position of coordinator for all deaf-blind services.

For the past several years, Edith Simon has advocated the need for a coordinator of

services for the deaf-blind citizens of Wisconsin. Recently the state agreed to establish this position, and is currently accepting applications. Ms. Simon is thrilled that Wisconsin will now provide at least a basic program for the deaf-blind which will grow and develop. She considers this one of the highlights of her years of work for the deaf and deaf-blind population in Wisconsin.

Throughout her career in advocacy, Simons underwent ongoing medical care and supervision for her sight. She became totally deaf in her early forties, and in 1974, she was totally blind for nine months. "The emotional cost for us all, Bob and the children, was wrenching," she says. Five surgeries to restore sight to her left eye failed, but one surgery on her right eye was successful. Although more surgery this past year further helped her sight, she has no depth perception, almost no peripheral vision, and fuzzy central vision. At present, "low vision" is a correct definition for her sight, but she says, "it's getting very low."

Despite her deep involvement in



advocacy and her disabilities, Simons has, over the years, earned enough college credits to put her in the junior year, and she expects to return soon to complete her education now that her three daughters are raised. Tragically, their only son died in 1980 at 29.



Edith and Bob Simons are the proud grandparents of Brandon, age 2, son of their youngest daughter, Pamela Barnes.



Simons attributes a "stiff upper lip" attitude and a lot of "Danish stubbornness," inherited from both sides of her family, for having helped her through the down periods. Deaf-blind people don't become "super" by virtue of their disabilities, she says. "We are still ourselves. Everybody has circumstances that hold them back - ours are just more visible. What is most heartening to me is the number of new people who are now involved, committed, and caring advocates."

## **BEYOND SILENCE**

by Robert J. Smithdas

Your fingers whisper into my hands,  
and as if a voice had spoken,  
this stillness I know is suddenly broken  
and my universe expands.

I have only the sun and wind and rain,  
and the scent of woods and meadows  
to tell me, here in the quiet shadows,  
that autumn is here again.

Silence is only golden when  
your touch and your words bring home to me  
small things that are part of my destiny  
and the lives of other men.









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**NAT-CENT NEWS**

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**EDITORIAL**  
**INFORMATION PLEASE!**

By Robert J. Smithdas, LHD, Litt.D, LHD

Finding sources of information about aids and devices that can make life easier and less frustrating for deaf-blind people appears to be an ongoing problem. In this age of rapidly advancing technology, there is no single comprehensive source that gathers together and catalogues what is currently available as assistive devices for people who are deaf-blind.

The most ambitious efforts to remedy this situation were the ICTA catalogue published in Sweden over ten years ago, and a listing compiled by the Canadian National Institute for the Blind, published a few years later. Neither publication has been reissued since they were first published. Since they first appeared, many new and improved items have been developed and are available - if one knows

where to find them.

Recently this writer received a report on aids and devices for deaf-blind users compiled by Dr. J.M. Gill of England for the World Blind Union. It contains product listings from various manufacturers and agencies in Europe and the United States, provides addresses and prices and gives brief descriptions of the items and the purposes for which they may be used. It includes information on aids and devices for communication, signalling systems, sound detectors, clocks and vibrators and aids for typewriters such as margin warners and end-of-page indicators. Unfortunately, the report does not provide specific details on operation and installation and it is only available in print. To use the report to best advantage, one will still need to contact the producers and sources of supply for complete details of operation for many of the items listed.

If readers of NAT-CENT NEWS are

interested in obtaining copies of this report, write to: Dr. John M. Gill, Royal National Institute for the Blind, Technical Development Department, 224 Great Portland Street, London W1N 6AA, England.

### **FIELD NOTES**

By Dennis Brady, Assistant Director, Field Services, HKNC

The second national conference on services for older adults, sponsored by HKNC, was held in Dallas, Texas, November 5-7, 1992. Martha Bagley, specialist to older adults, singlehandedly made this conference a huge success. The title was "Challenge To Independence: Access To Life Quality For Older Adults With Hearing and Visual Loss."

The conference was outstanding. The turn-out was approximately 200 persons and the participants were consumers,



rehabilitation teachers, specialists in aging, HKNC staff and affiliate personnel, audiologists, specialists in low vision and students. Commissioner Nell Carney from Rehabilitation Services Administration in Washington, DC, spent an entire day at the conference.

It was important that HKNC hosted this meeting. We recognize that older people need assistance for problems with visual and hearing loss. We are striving to bring together the people and services that can help them. There will be more information on this subject in future issues of NAT-CENT NEWS.

A recent change at HKNC involves the Affiliate Program. Rod Ferrell, originally with the HKNC affiliate in Arizona, has been hired as national coordinator of affiliated services. He is temporarily working out of the New York headquarters, but will eventually move to Washington, DC.

We plan to relocate HKNC's regional office in the Philadelphia, Pennsylvania, area to Washington, DC, in the near future. Cynthia Ingraham, regional representative, and Rod Ferrell will share the new regional office.

### **UPDATE ON HKNC AFFILIATES**

By Charles "Rod" Ferrell, Affiliate  
Coordinator, HKNC

I appreciate the opportunity to share information with readers of NAT-CENT NEWS and to represent the thirty-four HKNC affiliates.

The purpose of the HKNC affiliate network is to enhance the ability of the state and/or local community to serve the individual who is deaf-blind in his/her community setting. The affiliates reported serving 2,910 persons in fiscal year 1992, representing an increase of 10% over the previous year's total of 2,656 persons

served.

A consistent theme in this year's Affiliate's Reports was an increase in networking and teamwork. The clientele of the affiliates seems to be more handicapped, severely disabled persons who require more intensive, time-consuming and expensive services. Significant increases in the number of deaf-blind persons served is not expected for a few years, but significant increases in the number of service hours given for individuals with deaf-blindness can be expected. This increase will reflect more interagency effort and services to the individual and family members.

We often think of HKNC affiliates in terms of their interaction and efforts related to persons with deaf-blindness. Many of the affiliates, however, are persons who deserve recognition for other things. Carol Alberg, HKNC affiliate in Hawaii, is such a person. I am including



here Carol's vivid account of the effects of hurricane Iniki on the residents of the island of Kauai, the effects of volunteers on the recovery efforts, and the effects of the residents on the volunteers.

\* \* \* \* \*

September 11, 1992, started off with civil defense alarms resounding on the islands of Kauai and Oahu at 5:30 a.m. It was frightening to learn that Hurricane Iniki would be arriving that afternoon with 160 mph winds. As the afternoon approached, the hurricane changed course hitting only the Waianae coast of Oahu and heading directly toward Kauai. All communication was lost with Kauai for the rest of the day and night. It was distressing to know that the hurricane had hit full force on the island and not know how people were doing.

Later the next day, pictures and news started to trickle back to Honolulu. Stories were told of the destruction the hurricane had wrought throughout the entire island

of Kauai. However, no picture or story can compare with actually seeing the devastation and talking to the people of Kauai about their experiences through the hurricane and after.

The state's Department of Human Services handles the Individual and Family Grant Program for disaster victims and asked for volunteers to begin working at the eight disaster assistance centers on Kauai. Vocational Rehabilitation and Services for the Blind Division sent six volunteers to work with a team of people from the department. We were all anxious to help in this situation and had no idea what we would be confronted with when we arrived on Kauai.

When we arrived, we saw houses in crumbled piles, roofs and walls missing from homes, power lines scattered over the roads and debris everywhere. Working at the Disaster Assistance Centers was like working in a war zone. Army and National

Guardsmen were everywhere, helicopters were flying in and out, people were standing in lines to get food, water, clothes, tents, lanterns and financial assistance.

Working at the Disaster Assistance Centers from 8-6 daily allowed ample time to learn how much of a loss the people of Kauai had suffered. Throughout this time, story after story was told of losses of homes, personal belongings, everything some people had worked for all their lives. More disturbing were the fearful stories of staying in their homes as roofs and walls were torn away. A major problem expressed by many people was dealing with unemployment. Kauai is dependent on tourism and most of the tourism related industries were forced to shut down.

These people have endured so much and will continue to endure until their homes and lives are reconstructed. The Aloha spirit is still very much alive on Kauai.



People are thankful for whatever help they received. Many people came in to assist family, neighbors and friends. What little they had they were offering to others and big signs were posted throughout the island offering Mahalo (thanks) to the military and others who were helping.

### **HE TRIUMPHS OVER VISION AND HEARING LOSS**

By Barbara Hausman, Director of Public  
Relations, HKNC

Extremely competent, gentle and soft spoken, Henry Palmer was born in Abbingdon, PA, and moved with his family to Philadelphia when he was two years old. Though he was congenitally blind, he had perfect hearing. His parents discovered the Overbrook School for the Blind and Palmer successfully completed his education there in 1962. He soon found employment at

the Pennsylvania Association for the Blind in Chester, married his school sweetheart and became the proud father of twin girls. Tragically, his wife died a year later but Palmer remarried and then his family grew to include three more daughters. "My hearing began to fade when I was 25 years old," says Palmer. "It was very slow, it didn't happen overnight. Ten years later it was very evident that I really needed a hearing aid. I had trouble accepting it, but I did start to use it." Today his hearing loss is severe.

Though he performed several jobs at the Pennsylvania Association for the Blind - packing, riveting machine, inspector of shipping - he felt he hadn't reached his full potential in the job market, and needed further technical training.

In June 1991, one month following the death of his brother, Palmer was somewhat despondent, but entered the Helen Keller National Center (HKNC) in



Sands Point, NY. "I had to re-build my confidence after my hearing loss," he added. "My ability to communicate and be effective in the community was lost."



Former student, Henry Palmer (L) uses the TeleBraille to communicate with staff member, Anne Sedewitz (R).

At HKNC, Palmer learned new communication skills. He studied American



Sign Language, including fingerspelling (a series of finger and knuckle positions, each representing a letter of the alphabet, spelled into the palm of the hand). He learned to use special electronic devices like the TeleBraille, which outputs information in braille and can be used for face-to-face communication or as a telephone device. He can now access the computer with specialized software and modifications which enable him to read the print screen by converting it into a braille output. "I can type on the keyboard," Palmer noted enthusiastically, "and use every function that a sighted/hearing person does - move the cursor, read the window display and more."

In addition to working at the Company Store on HKNC's campus and modifying calculators for an outside vendor, Palmer's work experiences at the Center included teaching braille to new students and public speaking stints for adult and children's

audiences. He served for one year as an articulate and able chairman of the students' Town Hall Committee, which holds monthly open meetings to air students' views and "gripes."

What of the future? Henry Palmer has returned to his own apartment in Chester and will be working at the Touch Document Company, where he will turn print materials into braille for certain businesses, such as menus for restaurants and bills for the local electric company. As a result of his mobility training at HKNC, he will use public transportation, once again, to reach his job site.

Finding an appropriate job for Palmer resulted from the joint efforts of HKNC's staff and the Bureau of Blindness and Visual Services (BVS). In fact, BVS will be purchasing three pieces of equipment for Palmer to use "on the job" and at home - the TeleBraille II, the Teletouch, a small portable machine which permits one person

to type a message on a regular keyboard while Palmer receives it on a corresponding braille cell in the back of the device, and the Navigator, an electric braille access device for an IBM DOS computer.

Despite the loss of one of his daughters (from cancer) during his rehabilitation training at HKNC, Palmer, now age 51, continues to reflect positively. "The will to keep going ... that's hard sometimes ... but one has to function. I've had a lot of support at the Center. People were caring and interested." Palmer's words addressed to others with disabilities embrace his courageous outlook on life. "It's natural to feel frustrated, but you have to come to grips with yourself. You're here for a reason. Don't worry about what you CAN'T do, find something you CAN do and learn to do it well!"

Henry Palmer is available for interviews and photo opportunities. Please call Barbara Hausman at (516) 944-8900, or



HKNC regional representative, Cynthia Ingraham, in Prospect Park, PA, at (215) 237-1575.

## **WEDDING BELLS FOR A HAPPY COUPLE**

By Louise Jamieson

(Reprinted with permission from the  
Beverly Times Newspaper Co., Beverly,  
MA)

Henry and Lois Finocchiaro may be deaf and blind, however they're anything but silent. Sitting across a table from one another at the New England Home for the Deaf, the couple's hands move in a constant dance of conversation.

Henry, 67, and Lois, 68, are newlyweds. They met and fell in love just two years ago, and married last November.

In a world where love seems elusive for many, this remarkable couple has more than enough to share.

"We met in a church. He helped me so

much. He's such a good man," Lois said through an interpreter, speaking at times with sign language and at other times through the finger language she uses to communicate with her new husband.

"I taught her to use braille and to do the braille typewriter," Henry said. On the day Lois first came to the home in Danvers, he decided to help her.

"She didn't know where we were going. So I told her to hold onto my back and took her to lunch. I didn't want her to bump into any people," he said.

Today, they still make their way through the comfortable rooms of a rambling Victorian home in the same manner, linked together, feeling their way.

Although both lived their lives without hearing, blindness is a relatively new challenge. Lois, who was born deaf, lost her sight 12 years ago, and her first husband three years ago. She is the mother of two, and grandmother of three.

Henry was a toddler when he caught a cold that robbed him of his hearing. "My mother would scream into my ear and I couldn't hear her, so she brought me to the Rutland School for the Deaf in Providence, Rhode Island," he said. He lost his sight when he was 44. He never married until he met Lois.

It was Lois who proposed. Henry said "Okay," and presented her with a beautiful engagement ring on Christmas Day, 1990.

The wedding, Nov. 3, 1991, was "beautiful," said Lois. "I had a beautiful wedding dress."

More than 70 people attended at St. Joseph's Church in Framingham, MA, including Lois' daughter, Bonnie. There was a receiving line and Henry swears he shook hands with every guest.

And then they waltzed. "He loves to waltz," said Lois with a look of delight on her face. "Yes, I love to waltz," said Henry, chuckling.



What can an elderly, deaf-blind couple find to share? Hours of conversation - good conversation - to begin with. "We talk about everything together," she said. "We go to deaf-blind conventions together and we have a wonderful time. Two years ago we visited Virginia together," she said. Henry finishes her sentence to the amazement of his interpreter who has not told him what his wife is saying.

"We went to Williamsburg. We flew on a plane. It was a huge convention. There were more than 600 deaf and blind people."

In June they traveled to the Federation of the Blind convention in Charlotte, North Carolina. Henry read about it in a braille newspaper and decided they should go.

They also share work. Both of them work on a project sanding popcycle sticks and bundling them for use in candy apple kits. Henry also keeps busy teaching four kinds of sign language and braille.

And they share Lois' family. Henry loves it when Bonnie visits with her three children or when Lois' sister-in-law, who is married to a policeman, comes to call.

And Lois is looking forward to sharing Valentine's Day. "I love Valentine's Day," she admitted. She will wear the outfit she has put on for the interview - a red sweater vest and satiny red blouse with the garnet heart earrings and necklace Henry gave her for Christmas.

It will be a happy Valentine's Day for both of them, they say. They may not have their hearing or sight, but they do have each other.

### **WHAT'S LIFE ALL ABOUT**

By Barbara Hausman, Director, Public  
Relations, HKNC

For people who are deaf-blind, have had limited life experiences, lack formal communication systems and are often

"behaviorally challenged," each day of life can be difficult. But beginning in March of 1992, a formal L.I.F.E. program (Living Innovations in Functional Environments) was established at HKNC with its own staff of eight.

LIFE is a comprehensive, person-centered program for those individuals who require more intensive instruction in the areas of personal grooming, dining, meal preparation, work skills, leisure activities and communication. It occurs 24 hours/day and seven days/week - whether students are in their own apartments in the residence, out in the community or in the work training area at the Center. Staff integrates the needs of the students with their preferences and choices, as well as the reality of their future home and vocational options.

"The key to LIFE is matching students' interests with a task or real job," notes LIFE coordinator, Laura Rocchio. "That



guarantees success."

John Walters, HKNC supervisor of behavior modification cited one student, "C.M.," who prefers "movement" type work and expresses anger and frustration when doing work he doesn't like. "He loves contact with people, too, so the old traditional 'bench work' in a sheltered workshop isn't appropriate for him," says Walters. "He enjoys delivering mail and the lunches to the child care program. And then there's 'C.S.' who enjoys doing laundry and he's very meticulous, so we'll start him at the local laundromat with folding towels."

Presently, five students form a LIFE family. They prepare and share their own lunches and dinners, dine and clean together and interact with one another: "Can I get you a cracker? Can I take your plate?" . . . in a natural, not artificial setting.

"For the first time these individuals are

moving off campus and using their new skills," added Walters. "Even though there are some things they'll never do, like balancing a checkbook, they are reaching some level of achievement and acquiring 'survival skills,' such as food shopping twice a week for their own meals. They're not just performing 'busy work'."

"LIFE is a person-centered program," Rocchio emphasized. "We are trying to expose students to a variety of experiences to help them choose a preferred lifestyle."

What are LIFE's results so far? Fewer behavioral issues for staff, more participation by the individual in meaningful daily experiences on campus and in the community, and, eventually, acquisition of functional skills needed for successful living when the student returns home.

Another group of students, in the Current Events Program, meet to learn more about the world around them and, conversely, how they can have an impact

on their environment.

"Since many of our students have limited language and life experiences, their full understanding is also incomplete," says Miriam Domingo-Schmitt, HKNC clinical social worker, who leads the group. "They glean general ideas, not specifics. We want to broaden their knowledge base about the community, the nation, the world, and help them to understand how events affect them."

The students initiate topics for discussion and often share information from their hometowns. "R.B." brought in her Portuguese/American newspaper; returning from vacation, "G.H." brought back a cotton plant from Tennessee. Everyone had heard of AIDS. Some group participants had close personal experiences; some had misconceptions; a few had read about Arthur Ashe, so a full discussion followed. Last fall a volunteer from the Port Washington League of



Women Voters explained how to obtain an absentee ballot, how to register, how to vote. The group talked about the candidates and non-candidates. They are aware of names like Clinton, Bush, Perot, David Duke.

"It's so rewarding to observe the students developing a sense of confidence as they become more aware of what's happening around them," added Schmitt. "Even though their language levels are different, the participants are exploring concepts such as black vs. white issues in Africa, in the U.S., and within themselves. They also learn to use newspapers, TV, express opinions and ask questions. They're interacting socially with each other and sharing mutual interests that are 'fun'... topics like sports, gardening, cooking, as well as the dreary news of the day."

**HALLOWEEN HAPPENINGS AT HKNC**

By Allison Burrows, Editorial Assistant,  
NAT-CENT NEWS

In spite of the nasty October weather, some 5 to 6 thousand visitors from the Long Island/Metropolitan New York area braved the elements and found much to enjoy at the Center's third annual "Family Halloween Fair."

As in the past, the Haunted House was a great success and long lines of patient parents and children waited to be spooked by graveyards, bloody corpses, coffins, body parts, and very scary ghouls and ghosts - all in good fun, of course.

Along with over 200 volunteers from the staff and community, many HKNC students volunteered their time and entered into the spirit of the weekend by arriving in costume.





**Staff member, Meg Mandell and a friendly devil.**



**Staff member, MJ Shahren, enjoys a snack in the Haunted House.**



**Students, Chad Soares and Joyce Hickman, arrive in costume.**



**Students, Brad Cupit and Rosa Oliveira volunteer their help.**



Music and dancers, clowns, pony rides, costume and poster contests, a puppeteer, and games were some of the entertaining aspects of the weekend. In addition, visitors learned about deaf-blindness in the Communications Learning Center and the Daily Living Skills area where numerous aids and devices were being demonstrated and games could be played blindfolded.



Staff member Carol Dobson (R) plays a game of Othello with Imma Jordi (L), an Intern from Spain while Rod Ferrell (Center), tries his hand at a game with a blindfolded visitor.

Volunteers in the computer room explained the equipment and others brailled and

"fingerspell stamped" names for the children.



Staff member, Michelle Smithdas (in wig) reads a visitors name on the Tellatouch which she will then braille on a card. Volunteer, Beth Lewis (R) waits to stamp the visitors name on the card in the manual alphabet.



Volunteers, Adele Beck and Haruko O'Hara, try to stay warm while working at the bake sale.



A very successful bake sale of all homemade goodies and grills with hamburgers and hot dogs kept the visitors happily fed.

Halloween was celebrated safely at HKNC, and hopefully, our visitors became more aware and sensitive to the life of a person who can neither see nor hear.

**MY COMMUNICATION MODES: NO  
TECH, LOW TECH, AND HIGH TECH**

by Gail Anne Sabonitis

(Reprinted with permission of Disability  
Issues, a publication of the Information  
Center, Boston, MA)

Over the years I have used many communication modes and I communicate in varied ways. The first one is speech and speech-reading. When I was growing up my speech was encouraged and voice lessons continued until I was 20 years old. I can speak as normally as any hearing



person. Since I did not go completely deaf until I was 28, I was taught speech-reading, commonly known as Tadoma. This requires placing the thumb of the listener on the lips of the speaker. It is a very time consuming process. I do not use it any more because it is too tiring.

Another device I use is the Tellatouch, a typewriter-like device that has a small metal plate on the back of the machine. People can type to me on my Tellatouch and I can reply verbally. When the person types, the listener gets the message in braille, one letter at a time. This is slow but better than nothing.

I also use morse code. I am an extra class ham radio operator (the highest class of amateur radio license) and have had my license for 21 years. Despite my total deafness, I can understand and send morse code at 25 words a minute. I know code by heart and those who know it can code on my hand. I taught myself everything I

know in ham radio, even the morse code. I have communicated with many amateur radio operators in different states and a few foreign countries and can carry on conversations with friends in morse code. Nowadays, I only operate on weekends because it is tough to get to my shack (radio station), which is located in the basement of my house. Someone must help me to get down there and, since I tire quickly and must rest, there is not too much sense in going down to the station.

In 1982, I joined the Handi-Ham System out of the Courage Center in Minnesota. They have ham operators in each state to assist disabled people who want to become ham radio operators. They sent me a volunteer to help me with my station. After joining, I started helping blind people who wished to get into hamming. I would refer them to Handi-Hams and provide background help. This was a rewarding experience and I helped a few

people learn the fundamentals so they now have their ham licenses.

In 1984, my interest in ham radio grew into another interest - computers. I am self-taught in this area also. I started with an IBM PC computer in 1984, and progressed to a cassette VersaBraille in 1985 and then to an Apple II computer and modem in 1988. I published an article about my computer setup and invited readers to contact me for information on grants because I received a couple of grants from a private agency in Worcester, MA, in order to afford my setup. I could never afford it on my own finances - I'm on social security. Many people replied to this invitation and I was able to assist them in learning the fundamentals of computers and grants.

For those who don't know morse coding, they can use the fingerspelling of deaf people to communicate with me. They can spell into my hand. This not sign



language. I refused to allow anyone to teach sign language to me because it can be too tiring for me. Besides, how is a totally deaf-blind person supposed to look up forgotten signs?

People can also communicate with me by typing to me on my Apple computer which is attached to my cassette-driven VersaBraille. This is my own configuration. I communicate in the ways that are most comfortable to me. I had trouble with the rehabilitation experts because their focus seemed to be on speech and sign language. Not everyone knows sign language. I don't like getting involved with rehabilitation agencies because they have a way of getting into a person's private life and making them feel like commodities.

There are other means of communicating with deaf-blind people. I myself don't read "printing" in the palm of the hand, but I did just buy a box of plastic letters to give to a little deaf-blind child so

he can learn about the concept of reading. There is also a device called the talking hand (a device that fingerspells the letters you type onto a keyboard). Because of my neuropathia it is too delicate for me and also too expensive.

I can't use just any computer equipment so I have a consultant investigating options for when the company that makes the cassette VersaBraille can no longer fix it. With the computer a whole new world has been opened up for me.

Editor's Note: If you are interested in learning more about ham radio, you can contact the American Radio Relay League at 225 Main Street, Newington, CT 06111 (203) 666-1541.

## **NEW ZEALAND PLANS CONFERENCE**

The New Zealand Visual and Hearing Impaired Persons Society (NZVHIP) has announced plans for the first international conference on deaf-blindness ever to be held in New Zealand. The title and theme of the conference is: "Quality of Life and Independence for the Deaf-Blind and Vision and Hearing Impaired Into and Beyond the 21st Century."

The conference will take place in South Auckland, New Zealand, May 6 - 10, 1993. Accommodations are available at the Waipuna International Hotel and Conference Centre, which can accommodate up to 400 participants. The official language of the conference will be English and there will be no arrangements made for translation into other languages. A hearing loop and other assistive devices will be available as well as braille and large-print materials for those who require them.



Deaf-blind attendees should bring their own interpreters. There will only be a limited number of interpreters available for back-up interpreting.

The NZVHIP cordially invites deaf-blind attendees and their interpreters, professional workers, and civic and government officials to the conference. Discussions will be geared to helping adult deaf-blind persons improve their quality of life, and to spreading knowledge of technical aids and other devices which will help them achieve their goals and ambitions.

Those who wish to attend the conference should obtain registration forms and related information, and send in their forms no later than February, 1993. Contact Ms. Janett Scahill, Chairperson, International Conference on Deaf-Blindness, P.O. Box 23-749, Papatoetoe, New Zealand.

**THE TOUCH OF NATURE**

By Geraldine Espana

(Reprinted with permission of Newsday,  
Long Island, New York)

The sight of a budding rose may soon be a distant memory for Linda Carter. So she has learned the pleasures of the fragrance and texture of plants in the sensory garden at the Helen Keller National Center in Sands Point.

"You can really do anything you want to - even if you are deaf and blind," says Carter, who was born with a hearing deficiency and is gradually losing her sight because of a congenital condition called Usher syndrome. A recent "graduate" after 20 months at the Center for people who are deaf-blind, Carter, 30, has returned to her home in Florida, where she lives independently with her 6-year old daughter, Meagan. (Mother and daughter were the 1992 poster models for the Helen

Keller deaf-blind awareness campaign, named for the celebrated American lecturer and author who proved by example that deaf-blind people can lead satisfying, productive lives.

The sensory garden, a gift to the Center from the Sands Point Garden Club, serves as a place to enjoy a quiet moment with nature as well as a training ground in the Center's horticulture program. It adjoins a vegetable patch and greenhouse in a corner of the 25-acre campus, formerly part of the Guggenheim estate. Carter is the latest of the Center's clients who plans to seek a career in horticulture.

On a recent sunny morning, volunteers from the garden club helped deaf-blind students "discover" the fragrant new plantings. Carter, who still has some peripheral vision, playfully plucked a lavender blossom and tucked it in the hair of a young friend who is also visually impaired and deaf.



The fragrance garden, now in its 10th year, has just been revamped under the direction of Anthony Lepsis of North Hill Garden Design, Westbury, NY. Among the new plants are China Pink dianthus (a fragrant miniature carnation), old-fashioned Perfume Beauty and Yves Piaget roses, Stargazer lilies, heliotrope, daphne, sedum, yarrow, creeping thyme and fragrant hostas.

Originally designed by landscape architecture professor, Herbert Cohen of Farmingdale, the garden is bordered by 3-foot posts connected by rubberized chains that run along the flower beds. The posts are topped with braille plaques identifying the plants. Textured walkways of brick, stone, concrete and tanbark provide guidance from one textured or fragrant plant to the next. Raised redwood planters overflow with herbs that, when rubbed between the fingers, give off a lingering scent of lemon, sage, rosemary,

mint or chive.

### **WORTHY OF PRAISE**

(Reprinted from Brighter Horizons with permission from The Northeastern Association of the Blind, Albany, NY)

Sophia Mikowas, a deaf-blind woman who has been employed by the Northeastern Association of the Blind in Albany, NY, (NABA) as a sewing machine operator for 20 years, has been named Blind Worker of the Year by her fellow employees.

Ms. Mikowas will now be eligible to compete nationally for the Peter J. Salmon Award, given each year by the board of directors of National Industries for the Blind. This organization distributes government contracts among agencies employing blind labor throughout the United States.

Locally, Ms. Mikowas produces towels

and blankets for sale to the federal government. The contracts provide steady jobs to 18 blind people of Albany. "Many would probably not be working were it not for these government contracts", remarked Dr. Michael B. Freedman, NABA's executive director.

"Ms. Mikowas's selection this year is especially noteworthy," Dr. Freedman said, "since it coincides with the 50th anniversary of the passage by Congress of the Wagner-O'Day Act, legislation that mandates agencies of the federal government to purchase, under certain terms and conditions, products made by blind people in the nation's workshops."

More than 1,300 products are now on the Government Procurement List. They are as diverse as components for the Kevlar helmet, suture removal kits, gun slings and holsters, household and office supplies, aerosol paints and detergents - many of them items used in Operations



Desert Shield and Desert Storm.

The first national Blind Worker of the Year award was presented in 1968. The award honors Peter J. Salmon, a leader in the field of blindness, who worked diligently to improve services and opportunities, especially in employment. Mr. Salmon was instrumental in getting the Wagner-O'Day Act passed by Congress in 1938.

### **THE WORLD BLIND UNION ON DEAF- BLINDNESS**

The following article was sent to the editor by the World Blind Union, the international organization of the blind and visually impaired, which maintains a Standing Committee On Activities of Deaf-Blind People. As former chairman of the Standing Committee and now a consultant to it, your editor was keenly interested in the Committee's viewpoints on deaf-

blindness world-wide. It is commendable that an international awareness of deaf-blind people and their problems is growing.

An international conference on deaf-blindness, sponsored by the World Blind Union, is scheduled for October 1993, in Italy.

\* \* \* \* \*

### What is Deaf-Blindness?

A person is deaf-blind when his\her sight and hearing is seriously impaired. Some deaf-blind people are completely deaf and blind. Others have residual sight or hearing, or both.

Deaf-blindness is a severe handicap. A hearing impaired person usually compensates this with sight, and vice versa, but this is impossible if you are deaf-blind. When the two handicaps are combined, the possibilities of using any residual sight or hearing are greatly reduced.

Deaf-blindness makes social life difficult, and many deaf-blind people become isolated since they cannot communicate with their surroundings. Deaf-blind people also find it hard to obtain information through the means of newspapers, radio and television. It is also difficult to take part in cultural activities.

Education and employment are other areas where deaf-blindness causes difficulties. A deaf-blind person cannot take part in education for the blind or for the deaf without special support. Many jobs have to be specially adapted to suit deaf-blind people.

There are people who are deaf-blind in all countries, but in many places very few of them are known to authorities. From surveys carried out in several countries, it seems safe to conclude that out of every 10,000 people, at least one or two are deaf-blind.

Children who are born deaf-blind often



have other handicaps as well. Even if these children are severely handicapped, something can and should be done. The children benefit greatly from education and rehabilitation, and it is of the utmost importance that they are taught a method of communication. Among children who are born deaf-blind the most common cause is that the mother has had a virus infection, such as rubella, during pregnancy.

Most deaf-blind people become deaf and blind as adults. Accidents and diseases are the most common causes for loss of both hearing and sight. Usher syndrome, a hereditary disease, is a common cause of deaf-blindness among those who are born deaf. The disease attacks the vision and the result could be tunnel vision or total loss of sight. Among blind people who become deaf-blind as adults, the most common causes are accidents or diseases that impair the hearing. Infections of the

eye or ear that are not treated medically may also cause deaf-blindness. Whatever the causes, education and rehabilitation are of great importance to deaf-blind adults, as well as children.

Many people who are deaf-blind have lost sight and hearing due to old age. They need help in order to find a suitable method of communication. If this is not done, they may be severely isolated.

### Communication

There are several methods of communication. Which method a deaf-blind person uses usually depends on when in life deaf-blindness occurred, and in which order sight and hearing was impaired.

Sign language, where signs corresponding to words are formed by both hands, is the language of those who are born or have become deaf at an early age. The signs are "read" with the eyes. When vision is impaired, sign language can be read with the hands instead of with the

eyes, so that a tactile language is developed. Sign languages are national languages.

People who have lost their hearing as adults may use a manual alphabet. This means that every word is spelled out by forming a hand in different positions corresponding to the letters of the alphabet. Manual alphabets are national, but there is an international manual alphabet as well.

Deaf-blind persons who are born or become blind at an early age may be proficient at reading braille and can use braille as a method of communication when their hearing becomes impaired.

Deaf-blind people with residual sight may be able to read large black print on a white paper. To communicate with those without residual sight, you may print capital letters on the palm of the deaf-blind person.

People who are deaf-blind with residual



hearing may use this with the help of a hearing aid under the right conditions, i.e., when there is no background noise and when one person at a time is talking. Audio loops facilitate the use of residual hearing.

### What should be done?

It is important that surveys are carried out to ascertain the number of deaf-blind people in every country, and to locate them. On the basis of such a survey, services for the deaf-blind can be built.

Deaf-blindness is a severe handicap but deaf-blind people can lead rich and meaningful lives if they get the education and support that they need. Both deaf-blind adults and children need education. All deaf-blind people need a method of communication. They may also need training in mobility and daily living skills. Occupational training may also be of good use in many cases.

When you are deaf-blind, you often need the support from someone who is

proficient in different methods of communication, such as an interpreter. This lessens the risk of isolation and makes it easier to take an active part in society.

The situation for deaf-blind people today varies greatly from country to country.

In some developing countries, schools for people who are deaf-blind have been established. In Kenya, teachers for deaf-blind children are trained by the Kenya Institute for Special Education, and deaf-blind children are diagnosed at the assessment centers that exist in the country. Deaf-blind children can then be taught communication and mobility among other things at Kabarnet School for the Deaf-Blind. The students also learn how to make their living. Other African countries have shown great interest in the school, and in the future such schools may be established in several other places.

In India, The Helen Keller National

Institute for the Deaf and the Deaf-Blind can be found in Bombay. In this school, deaf-blind children are taught the basic skills they need in order to function. The school is now serving as a pattern when similar schools are planned in other parts of India.

Both schools, the one in India and the one in Kenya, serve as centers of knowledge and advice.

In Latin America, efforts are being made to locate deaf-blind people and to establish what services and what education is available. Teachers who work in schools where there are deaf-blind students are educated so that they are better equipped to teach these children. This is being done both by training courses for the teachers, and by the distribution of information.

In some countries, deaf-blind people run their own independent organizations and work to improve political and social



conditions. This is possible in countries where the social services are so developed that deaf-blind people can take part in society on more or less the same terms as everyone else. In many other countries, deaf-blind people are members of the organizations for the deaf or for the blind.

Do you want to find out more about deaf-blindness?

Within the World Blind Union there is a committee on deaf-blindness - The Standing Committee on Activities of Deaf-Blind People. All the continents are represented on the committee, and the members work to improve the situation for deaf-blind people all over the world.

Every four years, the World Blind Union arranges an international conference where deaf-blind people meet to discuss important issues, The Helen Keller World Conference on Services to Deaf-Blind Persons.

IAEDB, the International Association for the Education of the Deaf-Blind, is an association for professionals. The IAEDB publishes a journal called "Deaf-Blind Education" and arranges conferences and meetings in order to discuss education and spread knowledge.

The following institutions can provide information and, in some cases, training: SENSE in England, Perkins School for the Blind and the Helen Keller National Center in the United States.

### **HAPPINESS IS A SPECIAL NEEDS PROGRAM**

(Excerpts from the North County News,  
Yorktown Heights, NY, by Kathy  
Grantham, and GUIDE LINES, Guiding  
Eyes for the Blind, Inc., Yorktown  
Heights, NY)

There wasn't a dry eye in the house when Janie Smith - a recent graduate of

Guiding Eyes for the Blind (GEB) Special Needs Program - told her story at the graduation ceremony. Janie, who is blind and deaf, had been turned down by a number of guide dog organizations before she came to Guiding Eyes for the Blind in Yorktown Heights, NY. Thanks to many generous supporters, a Special Needs Program has been developed that helps people like Janie.

The program provides specially trained guide dogs to men and women who, in addition to being legally blind, have other medical or physical difficulties. Hearing loss,



Janie and Dunbar



orthopedic problems, artificial limbs or neurological dysfunctions may be some of the additional challenges the blind students face.

Someone like 31 year old Janie, a cheerful young woman with a wide smile, is being helped with a guide dog and, for a while longer, can read one bright line of print on her miniature teletype display with keyboard. Her mainstay for communication is tactile signing, but typing reaches more people who don't know how to sign.

By the age of nine months, Smith's parents knew she was deaf. At the John Tracy Clinic for Deaf Children she learned to speak and lip read. By the age of 2, her vision was going and she wore glasses and a hearing aid to learn different sounds.

Smith attended Golden West College in Huntington Beach, California, and is a certified office technician and a rapid typist. Married, she has three daughters,

including identical twins.

She has always been part of a deaf world, but now her eyes have gotten worse and she's learning to live in a deaf-blind world. She has been diagnosed as having Usher syndrome, a combination of being deaf and blind that is supposedly the result of a recessed gene in each parent. She attended the California School for the Deaf where she learned lip reading and tactile signing and received independent living skill training at the Helen Keller National Center in NY.

The final straw was a recent diagnosis that showed the retina becoming detached and her doctor advised, "Go to Guiding Eyes for the Blind and get a dog." Her response was, "Amazing, I never heard of that. There's nothing in California for people who are deaf and blind."

She never felt safe with a white cane and Guiding Eyes understands her fear of being hit by cars. "At first I felt clumsy

and awkward, almost losing my balance, struggling with traffic, but Ted (Zubrycki, her instructor at GEB) said the dog would balance me."

She was overwhelmed at the way Dunbar, her guide dog, knew how to weave in and out of crowds and how to cross streets. "Now I trust Dunbar. Even if there's a cat around, I know how to get his full attention."

Michael Brennan, 45, from Chanhassen, Minnesota, also suffers from Usher syndrome. Born with a hearing loss, he wore a hearing aid and had speech training when he was 5. His vision went bad when he was 20, but really worsened 20 years later. Accustomed to being deaf, it was not until he began to lose his sight that he, too, was diagnosed as having Usher syndrome.

Adept at public speaking and working in management, he switched careers to accommodate changes in his physical



condition. Brennan had been a manager at Sears then, as his hearing worsened, he turned to woodworking and soon became manager of a small woodworking company. Considering his impending loss of vision, he felt it was time to turn in the cane and applied to GEB to train with a guide dog.

Still somewhat able to function visually, he started learning visual signing 16 months ago and now takes lessons in tactile signing five days a week through a private organization in Minnesota called "In Touch," whose purpose is to work with the deaf-blind community. "I sat down a year ago and tried to map out where I wanted to go, what I wanted to do with my life," he said. Public speaking is a strength he draws from and his speech is amazingly clear, completely unlike the speech of a profoundly deaf person, because speaking well has been one of his passions.

"I've never been bitter, because it

doesn't help. I've always tried to accept changes, to face them and do the best I can. I have a wonderful family, my wife is a nurse in a hospital in the newborn nursery and we have four children from 16 to 22 years of age. Everyone is A-okay."

Ready to work on his third career change, Brennan, accompanied by his guide dog, Clifton, will enroll in the fall at Gallaudet University in Washington, DC, to study rehabilitation counseling, a two year course. He can put all his skills to work in this career. There's a severe shortage of counselors skilled in working with the deaf, blind and deaf-blind, and he can speak out, acquainting the rest of the world with their needs, their struggles and their accomplishments. Upon returning to Minnesota, he'll relate his Guiding Eyes experience at a statewide deaf-blind workshop under the aegis of Dr. Sandra Davenport.

Ted Zubrycki, director of the Special

Needs Program, has 30 years of experience in the guide dog field. "I have always been interested in this area of service and I am thrilled to head this program," says Ted. "It allows us to help a segment of the blind population that otherwise could not receive a guide dog."

The success Janie and Michael experienced with their guide dog is based in part on the fact that each dog selected for the Special Needs Program receives approximately six months of intensive training designed for a specific student's unique requirements.

"Just as not all dogs can become guide dogs," says Ted, "Not all guide dogs can become special needs dogs." These dogs have added responsibilities and must demonstrate good working skills and respond effectively to the challenges he and his human partner face daily as a working team.

The Special Needs Program closely



parallels the rigorous training of the regular 26-day residential program. The strengths and weaknesses of each student are analyzed and these problems are duplicated during one-on-one training. Each team of blind person and guide dog progresses at its own pace. If needed, additional work is done after graduation in the student's home area. In emergencies, Guiding Eyes sends an instructor directly to the graduate's home, at their own expense.

During the two years this program has been in existence, they have seen over and over again that a special needs team of blind master and guide dog requires unique training and special matching of skills and tolerances.

## **HERE AND THERE**

ONE WAY OR ANOTHER: A GUIDE TO INDEPENDENCE FOR THE VISUALLY IMPAIRED AND THEIR FAMILIES, by Vivian

Younger and Jill Saregona, is now available. The book was especially written for newly visually impaired persons and their families. It provides practical information on how to cope with loss of sight and blindness. The price is \$15.00. Contact: Saregona Products, 710 Almondwood Way, San Jose, CA 95120; Telephone (408) 997-2150.

\* \* \* \* \*

The Equal Employment Opportunity Commission, a government agency, now has available a booklet entitled YOUR RIGHTS AS AN INDIVIDUAL WITH A DISABILITY. It is an outstanding resource for anyone interested in becoming more knowledgeable about reasonable accommodation under the Americans With Disabilities Act. The booklet may be ordered in braille, large print, audio cassette, or computer disk. Contact:

EEOC, 1801 L Street, N.W., Washington, DC 20507; Telephone (202) 663-4395 (voice), or (202) 663-4399 (TDD).

\* \* \* \* \*

A braille edition of THE OFFICIAL VERMONT MAPLE COOKBOOK is now available in one volume for \$8.00. The book contains a variety of recipes from maple nut bread to Vermont spring chicken. Contact: Massachusetts Association for the Blind, Braille Dept., 200 Ivy Street, Brookline, MA 02146; Telephone (617) 738-5110.

\* \* \* \* \*

American Greetings Corporation is expanding its line of greeting cards for the visually impaired. Currently, it offers large-print birthday, sympathy, get-well, and holiday cards. Check your local stores for



availability.

\* \* \* \* \*

Braille Sterling, "Jewelry With a Special Touch," is crafted in sterling silver and gold-plated silver. Some messages appearing on earrings include: "Happiness/Celebrity"; "Live, Laugh, Love"; "I Love You"; "Harmony/Serenity"; "Love God". Pendants and earrings range in price from \$25.00 to \$65.00. For a list of products, or to order, write to: Braille Sterling, Christiansen Studios, P.O. Box 583, Hanover, NJ 03755; Telephone (603) 643-1344.

\* \* \* \* \*

A new push-button padlock, which opens when a series of clearly-defined buttons are pressed, is now available from Lock-R-Lock. No keys or combination dials are

used. The user pushes buttons that correspond to a factory-set combination. The 15-button locks sells for \$6.00, plus \$1.50 shipping; a smaller 10-button model sells for \$5.00. Volume discounts are available. Contact: Lock-R-Lock, Hilltop Associates, Customer Service, P.O. Box 273, Grinnell, IA 50112; Telephone (515) 236-6828.

\* \* \* \* \*

Nurion Industries has announced the redesigning of its laser cane. The cane is lighter, slimmer, and collapsible. It features a standard rechargeable battery. To obtain further information, contact: Nurion Industries, Station Square Three, Paoli, PA 19301; Telephone (215) 640-2345.

\* \* \* \* \*

The Safe-t-Cane is a folding cane which features a xenon strobe light in the handle. When the user chooses to have the light turned on, it can be seen for up to two miles. The canes elastic cord and tip are easily replaced. The price is \$65.00. The same company also offers a nonlighted collapsible cane for \$20.00. Contact: Bossert Specialties, Inc., P. O. Box 15441, Phoenix, AZ 85060.

\* \* \* \* \*

The Chocolate Experience Company has introduced a new, exciting idea - braille chocolate bars! Hand-crafted and gift-wrapped, the treats are made of quality Stokes and Van Leer chocolate, and are available with messages such as "I Love You", "Happy Birthday", "Merry Christmas", and "Happy Holidays". Additional greetings will be added in English and Spanish. Choices are semi-



sweet, milk chocolate, and white chocolate at \$2.25 per bar, plus shipping. Sugar-free milk chocolate or white chocolate bars are also available at \$3.25, plus shipping, per bar. To order, contact: The Chocolate Experience, 150-75 Bayside Avenue, Flushing, NY 11354; Telephone (718) 461-1873.



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**NAT-CENT NEWS**

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# **EDITORIAL**

## **SUCCESS IS A CHALLENGE**

By Robert J. Smithdas, L.H.D., Litt.D., L.H.D.

His name is Jerome. He was a spare, spry man in his early fifties, with a remarkably mobile face that could change expression as easily as a chameleon changes color.

I met Jerome in 1962, when he came for training at the Industrial Home for the Blind in Brooklyn, NY, where I served as associate director of Services for the Deaf-Blind. He was from Putney, a small town in the high country of Vermont, famous for its marble quarries, basket shops and Putney apples. Totally deaf and with only light perception, he had only a limited vocabulary but was fluent with gestures and signs and could make himself readily understood. He also had the wonderful hands of a craftsman and an instinctive grasp of how to use tools and create useful projects.

Shortly after Jerome arrived, I organized a hobby shop in the residence where the

deaf-blind men lived so that they could spend their evenings and weekends working with their hobbies. The project was an instant success and several of the deaf-blind residents displayed unexpected skills in working with wood, tiles and clay. Jerome, in particular, showed unusual talent: he built a large tool cabinet and stocked it with power tools he purchased with his weekly savings and then proceeded to construct various projects in wood that he designed himself. He accumulated a wide assortment of hand and power tools which he used with skill and enthusiasm.

When my assistant, Herb Lehman, and I said goodbye to him, we thought it would be the last we would hear of Jerome.

A few years later, while attending a meeting in New England, I was approached by a deaf social worker who asked if I knew of a deaf-blind man named Jerome who lived in Putney, Vermont. When I told him that Jerome had been one of my clients in Brooklyn, he told me the following story.

Jerome had lived with his brother for two years, but there had been friction between them. Finally, Jerome decided to live alone; he asked for a small plot of land close to his brother's house. Then he made trips to the local lumber yard, purchasing various building materials and supplies himself. Singlehandedly, he began construction of a small two-room house, doing all the work himself. The only thing he couldn't do was paint the cabin and install the necessary plumbing and electrical wiring.

Although I knew Jerome was a skilled woodworker, I was amazed that he had undertaken such a large project - one that would be difficult for a sighted and hearing carpenter. Obviously, the social worker was equally impressed. "I know it's hard to believe," he said, "but Jerome built that cabin doing most of the work himself - floor, walls and roof."

Jerome is gone now. He died a few years ago at the New England Home for the Deaf-Blind. But he has left a legacy - a reminder that anything is possible until



proven impossible, and that the human spirit can achieve exceptional goals. And though their accomplishments may seem less dramatic, there are other deaf-blind individuals who have proved, and are proving, that ingenuity and creativity can overcome the odds.

## **FIELD NOTES**

By Dennis Brady, Assistant Director,  
Field Services, HKNC

We are pleased to inform you that the Helen Keller National Center opened an office in the Washington, DC, area on May 1, 1993. It will take a while before we are completely moved in, but this is an important step for HKNC. As a national agency, it is important that we become more visible and better known in our nation's capital.

We have moved HKNC's East Central Regional office to the new address from its former location in the Philadelphia area. Cynthia Ingraham, the regional

representative, will continue working in the same six states of the region. With her office located in the metropolitan area of Washington, we hope there will be more awareness and publicity on accomplishments and service needs of people who are deaf-blind.

Rod Ferrell, who is the national coordinator of HKNC's Affiliate Services, has been working out of the Center's headquarters in Sands Point, New York. He will also be moving to the Washington area office. His responsibilities remain the same, but now he will have easy access to government agencies. For example, if the Department of Education (DOE) wants some information that our Affiliates might have, he will be able to meet with DOE staff personally to answer questions and discuss issues, or provide information that previously could only be done over the phone or with a written report.

The address and phone number of the new office is: Helen Keller National Center, East Central Region, 6801

Kenilworth Avenue, Suite 100, Riverdale,  
MD 20737, Telephone: 301-699-6255  
(Voice), 301-699-8490 (TTY).

We have mentioned a few examples of how Cynthia and Rod will be able to do their regular jobs and at the same time take advantage of being in the Capitol. Additionally, having an office in Washington, DC, allows HKNC to work with various coalition groups that can influence decisions that affect the lives of people who are deaf-blind. This responsibility falls primarily to Joe McNulty, who is director of the Helen Keller National Center.

The opening of a new HKNC office in Washington is an important accomplishment for our agency. With this move, HKNC has eleven locations throughout the country: Sands Point, Boston, Washington, Atlanta, New Orleans, Dallas, Kansas City, Chicago, Denver, Los Angeles and Seattle.

Another item of interest is that HKNC's Technical Assistance Center has hired a



new program associate. Joan Houghton is currently working at the Center's headquarters in Sands Point, but will shortly be working at the HKNC Great Plains regional office in Kansas City. HKNC-TAC now has staff in four locations which makes it easier to provide service throughout the country.

## **HELEN KELLER'S VISION AT WORK**

By Barbara Hausman, Director, Public  
Relations, HKNC

Share Helen Keller's vision by participating with agencies and organizations worldwide in the HELEN KELLER NATIONAL CENTER'S 1993 AWARENESS CAMPAIGN which focuses on accessibility in the workplace and employment opportunities for people who are deaf-blind. Hiring a person who is deaf-blind brings more than just good work to the business that employs that individual. It promotes better understanding, cooperation and goodwill

among all employees. It educates the work force and dispels misconceptions, stereotypes and unfounded fears about working with people who have severe sensory impairments or loss.

Originally proclaimed by Congressional resolutions and Presidential signatures in '84 and '85, AWARENESS activities and events featuring information about significant vision and hearing loss or deaf-blindness now occur throughout the year, beginning in June, the month of Helen Keller's birth date.

Bradley Cupit, who is deaf and legally blind, is the 1993 AWARENESS poster subject. During his rehabilitation training at



A young adult like Bradley Cupit, who is deaf-blind, brings more than just good work to business. He promotes better understanding, cooperation, and good will among all employees.

the Helen Keller National Center, he explored several "real" work options and found that he preferred data entry work. He practiced inputting information on a sample Avis customer profile form using a computer, a CCTV (closed circuit television which magnifies print), and VISTA, a special enlarged text system. After his work experience at Avis' headquarters in Garden City, NY, proved so successful, he was offered employment and is now earning a competitive salary. He lives independently in an apartment rented by HKNC in the local town, where he is learning to manage a household before completing his training at the Center and returning home to Louisiana and employment in the data entry field.

"Since Avis has a long standing commitment to offering access and opportunity to people with special needs, we're especially proud to have had Bradley as a member of our staff, and through our actions, serve as an example to others in business and industry," said Joseph V. Vittoria, chairman and chief executive



officer of Avis, Inc.

During the past two decades, educational and vocational training opportunities for individuals with disabilities, including those with deaf-blindness, have greatly improved while employment opportunities in the private sector have not. Despite important full participation initiatives in the 70's and 80's, a national poll conducted by the highly regarded Louis Harris Company proved that the common thread of disability in America is unemployment.

The overall focus of the recent far-reaching civil rights law, Americans With Disabilities Act (ADA), is the empowerment of individuals with disabilities to achieve economic self-sufficiency, independence and inclusion into society. President Clinton said, "Our entire nation will share in the economic and social benefits that will result from full participation of Americans with disabilities in our economy."

Yet, accessibility in the workplace means more than just breaking down physical barriers. Training and job preparation are

vital components to employment, but there's also a "people" component - a willingness to change employment practices and address "reasonable accommodation" and services. "Substantial employment is attainable for people with deaf-blindness and over the years the number of options available to this population has grown," noted Jeremy Burwell, former HKNC senior placement specialist. "Unfortunately, not enough 'supported employment' programs throughout the states are receptive to providing their services to people who are deaf-blind."

All citizens, civic groups, libraries, schools and organizations are encouraged to plan state and local activities during the month of June, and especially during the week of June 20-26. A sample proclamation, a radio public service script, list of suggested activities, 1993 poster and ad slicks, and this press release are available at no cost from the Public Relations Department, Helen Keller National Center, 111 Middle Neck Road, Sands

Point, NY 11050, or by calling (516) 944-8900, ext. 325 (TTY & Voice).

**THESE ADULTS ENJOY INDEPENDENCE**  
(Reprinted with permission from The New  
Jersey Association of the Deaf-Blind  
Newsletter, East Brunswick, NJ)

Steve commutes daily to a job in East Brunswick, NJ, and shares a house with 3 other roommates, who all help with cooking and cleaning. Sounds like your average, suburban household, right?

Well, yes, except Steve is also deaf, legally blind, in a wheelchair and on his own for the first time in his life.

Steve, 28, is one of 4 disabled adults living in a newly renovated group home in Franklin, NJ. The 3 men and 1 woman, ranging in age from 27 to 29, are also blind and deaf. They were assigned to the home by the New Jersey Association of the Deaf-Blind (NJADB), a private organization based in East Brunswick that funds group homes.



Speaking for Steve, whose last name was withheld at the request of the association, a sign language interpreter said he lived previously at an institution in New York. Before that he lived in a New Jersey developmental center. Steve said he liked the staff, his co-workers at Our-Co in East Brunswick, and his roommates. "I was very excited and happy to move here," he said.

Group homes, like the one Steve now occupies, are generally considered one of the healthiest living arrangements for people with mental and physical disabilities because they encourage more socialization while providing people with a measure of independence that is impossible in institutions. And because they are smaller and more structured than other types of community-based housing, group homes send fewer of their clients back to institutions.

But social service agencies have also had to battle community opposition to the homes, which more often than not are in quiet, middle-class neighborhoods where

perceptions of mental and physical disabilities can become distorted.

Vicky Woodhull Calabro, executive director of the NJADB, said her organization has been lucky so far, encountering no roadblocks from neighbors. Several attended a party to officially dedicate the group home, the association's fourth.

NJADB, which receives most of its funding from the state, opened its first two houses in Spotswood and New Brunswick in the mid-1980's. A third opened in Bound Brook in May, 1992, and the Franklin one followed a month later.

Calabro said she is unsure how many people with both sight and hearing disabilities are waiting to move into group homes, although the State Department of Human Services said the waiting list for federally subsidized housing has more than 1,000 names on it. Many of the people on the list have physical and mental disabilities.

NJADB said many of its clients have been forced to remain in out-of-state

rehabilitation centers because their home state does not have suitable housing available.

Calabro said the Franklin home, a single-story brown and tan house with a spacious front lawn and pool in back, was purchased for about \$160,000. Renovations usually run at least another \$40,000, she said. Throughout the 4 bedrooms, family room, kitchen, dining room, den, laundry alcove and small office are examples of improvements specially designed for the disabled. For example, a fire alarm system both sounds and flashes. Special overhead lights emit less glare. Kitchen appliances, counter tops, sinks and bathtubs are wheelchair-accessible. Even the numbers on the microwave have special, raised borders.

Support staff are on hand day and night, although the goal is to have the disabled residents live as independently as possible.

During the day the residents all commute to a newly formed company in East Brunswick called Our-Co, short for Our Company. Twelve of its 15 workers are



disabled, and many have multiple disabilities. The workers' disabilities haven't stopped them from doing fine work, reported Tilghman Laubach, general manager of the company.

Our-Co has formed joint ventures with four different companies to do packaging and light assembling, said Laubach. One company makes country-western children's wear and toys, another audio visual tapes and binders, and a third prints plastic promotional items.

Laubach, who retired recently from Ford Motor Co., calls Our-Co the most rewarding job he has ever had. "Each person is searching for their maximum," he said.

EDITOR'S NOTE: Steve was a former student at the Helen Keller National Center.

## **LEGISLATIVE UPDATE**

by Barbara Hausman, Director,  
Public Relations, HKNC

Several major breakthroughs concerning services for people who are deaf-blind have recently occurred. According to Joseph J. McNulty, director, Helen Keller National Center (HKNC), "Legislators and professionals are now looking at people with deaf-blindness and recognizing that this population does have unique needs, and our ability to address these needs is growing rapidly."

As a result of the passage of the Helen Keller National Center Act as amended in 1992, the definition of deaf-blindness has been expanded and now includes a progressive loss of vision and/or hearing. It also states that any individual who cannot be tested for vision or hearing loss due to cognitive or behavioral restraints, or both, but functions as a person with deaf-blindness, is now eligible for services. The HKNC definition of deaf-blindness is used by all state vocational rehabilitation

systems. The Act specifically says that training for family members with individuals who are deaf-blind is needed to help them "obtain and provide appropriate services" for their sons and daughters, siblings or parents. This newly legislated "purpose" for HKNC reflects the Center's past activities which included the development of a National Parent Network in response to parent needs.

Included in the HKNC Act was the establishment of an Endowment Fund to help ensure future financial independence for the Center. The federal government will match funds contributed by the general public to HKNC, but there will be a "cap" on the annual amount, similar to the endowment funds created for Gallaudet University, National Technical Institute for the Deaf and American Printing House for the Blind.

For the first time the Rehabilitation Services Administration (RSA) has recognized deaf-blindness as a single and primary disability in their coding system. Before this breakthrough, individuals could



have been coded under just deafness, just blindness, or some other disabling condition such as mental retardation. This made it difficult to determine the number of people with deaf-blindness who were actually served. This critical coding change was achieved through the coordinated efforts of HKNC's Virginia Affiliate Paige Berry; HKNC Assistant Director Dennis Brady and Regional Representatives Sue Olson and Cynthia Ingraham; Regional RSA Commissioners Jim Dixon and Ralph Pacinelli; RSA's Chet Avery, Director, Bureau for the Blind and Visually Impaired and Wally Babington, Chief, Deafness and Communications Disorders Branch; and Tony Spinelli, RSA State Representative, Region II.

Under the Vocational Rehabilitation Act as amended in 1992, federally funded interpreter training programs now include preparation to serve people who are deaf and deaf-blind, not deaf or deaf-blind. Sponsored by the National Coalition on Deaf-Blindness, whose Chairman is Mike Collins from the Perkins School for the

Blind and Vice-Chair is HKNC's Director McNulty, this new directive must still define the different modes of communication used by people who are deaf-blind such as the manual alphabet, American Sign Language, or tactual ASL.

What does this all mean to service providers and our targeted population? Today all states and territories are able to serve the many individuals with deaf-blindness who in the past were considered ineligible. People can also be identified as deaf-blind early in their rehabilitation program, and then appropriate planning can take place by the educational and vocational systems, as well as by consumers and their families. These accomplishments may appear to be small steps, but they have a major impact on many people and many systems.

# **DREAMS BECOME REALITY AT HKNC**

By Anne Sedewitz, HKNC

Rehabilitation Counselor/Case Manager

## **Part I - Linda Becomes Independent**

Last year, I had the privilege of working with a lovely young woman, the mother of a five year old daughter. Diagnosed with Usher syndrome, Linda was struggling with the fear of an uncertain future. After her divorce, and never having lived alone, she became very dependent on family members and doubted she could live and care for her daughter independently.

After an evaluation at the Helen Keller National Center (HKNC) and one training period, Linda moved into an on-campus Independent Living Experience (ILE), apartment. Training was going well, but the separation from her daughter, who was staying with grandparents in another state, became too difficult. A decision had to be made; either terminate training or bring the child to New York.

After much discussion, it was decided that Linda would rent an apartment in the



local community, enroll her daughter in school for a year, and continue training. This was the beginning of a difficult but wonderful learning experience, not only for Linda, but for our entire staff. We experienced first hand some of the difficulties encountered when a person with a disability attempts to live independently in the community. And, as a result of this shared experience, we have developed a new program with many additions to our curriculum, expanding opportunities for future students at HKNC. This program will be explained later, but first, with Linda's permission, a few shared experiences.

Our first challenge was dealing with the Department of Social Services (DSS). Although I had contacted them many times regarding students' benefits, this was my first experience opening a case. It was a nightmare! I made numerous calls to get estimates for New York State Supplemental Security Income (SSI), Aid for Dependent Children (AFDC), and food stamps. The standard answer was, "We

can't give you estimates until the case is open, and we can't open the case until the person resides in the state." This is a Catch 22! How does one rent an apartment when they don't know their income, and can't determine their income until they have an apartment?

After days of frustration and repeated calls, I finally found a sympathetic ear and got ballpark figures. Based on these, we looked for an apartment. Luckily, Linda's parents came to visit, helped find an apartment nearby, bought furniture, signed the lease and paid the two months security. Right! Linda was not going to be independent yet - but she also hadn't completed training!

Now we had a legal address and our first date with DSS. After waiting an hour, we were given a six page application and two books of explanation, all of which were complicated and confusing. Upon completing the application to the best of our ability, we were told to return the following week with numerous documents. This was impossible because some had to

come from out of state and other were local utility bills and bank statements which Linda didn't have because she hadn't even moved in yet. During the next month, we spent three mornings at DSS, doing three identical applications, answering the same questions, and providing three identical sets of documents. The reason for this wasted duplication of paper and time is beyond my comprehension, especially since everything went into three identical computers approximately fifty feet from each other. Linda then waited two and a half months to receive all of her benefits. Without help in going through the process, and without financial assistance, Linda could not have done this alone.

The next challenge was transportation. There was no public transportation between the apartment and HKNC. Cab fare was too expensive so together we arranged volunteer drivers - not an easy task. Some were very faithful, but finding volunteers and arranging substitutes, especially on short notice, was very



difficult. Access to public transportation or paid assistance is a "must" to be truly independent.

When school started in September, a host of other problems developed. There were many forms to be filled out, including a medical history form. Linda came to me, embarrassed because she was unable to complete the form after filling in her daughter's name, address and birth date. She was unable to read the list of childhood diseases and other medical conditions. Although familiar with a few - chicken pox and mumps - she did not know the meaning of pneumonia, arthritis and other common illnesses. Later, when I accompanied her to the pediatrician for her daughter's school physical, I understood the problem. Linda was attempting to read a children's book to her daughter and was stumbling over many of the words. It suddenly dawned on me that she was functionally illiterate. This explained the many times she nodded, appearing to understand something when she really didn't. Staff members, myself included,

thought it was her hearing, when in fact she was too embarrassed to admit she didn't understand.

We spent a lot of time talking about this. It was vitally important that Linda understand that it wasn't her fault. Her problems stemmed from a poor educational background. Linda was an intelligent, creative and capable young woman. The fact that she couldn't read was due to a school system ill equipped to deal with a deaf youngster. She had been placed in a special education class and sat, understanding nothing.

I asked the Communications Learning Center (CLC) for assistance, and after further discussion with Linda, contacted Literacy Volunteers of America and arranged for a tutor. A wonderful young college student worked successfully with Linda, three hours a week for the next several months.

Often, I found Linda nervous and apprehensive, waiting at my office door early in the morning. She had numerous questions, most concerning mail or

correspondence from her daughter's school or day care center. After consultation with Linda's CLC instructor, one class was set aside each week to go over all correspondence, including "junk" mail. Linda was taught to use a dictionary and thesaurus to look up words she didn't understand and she kept a spiral notebook with a list of new vocabulary. With great determination, Linda listed every word she heard on TV or read in the newspaper that she didn't know and wrote the definitions in her notebook. Toward the end of the year, Linda was almost totally independent in handling her mail.

Banking and budgeting was another vital area of concern. We worked out an estimated budget, and I appealed to CLC for help in monitoring Linda's finances. The instructor set up a system for recording weekly cash expenses and monitoring her checkbook. Linda did an excellent job of paying her bills on time, but had no idea how to maintain records. When asked to see a bill or receipt, she would bring in a stack of envelopes and



search through for the right bill or bank statement. Back to CLC to request help with a filing system. How proud Linda felt when she showed me her portable file with everything organized!

One unexpected problem was incoming phone calls, both telemarketing and crank calls. Having considerable residual hearing when aided, Linda used a regular phone and TTY. She had no idea how to handle calls from strangers - something we had not dealt with previously.

Another problem Linda encountered was mobility. Although she had already received mobility training, once her daughter arrived she had difficulty using the cane while holding her daughter's hand. It became even more difficult when trying to maneuver her grocery cart or laundry cart. More mobility training was needed for mother and child.

At times, Linda felt overwhelmed. Between school, work, homework, her daughter's homework, keeping house, parenting, etc., there was little time for herself. The clinical social worker dealt

with many of these issues, and as Linda began to relax a little, her confidence increased. She began to take pride in her new abilities and understand that many of her problems were directly related to educational deficits that were not her fault.

Gradually, Linda became more and more independent. She did an outstanding job as an intern in our Creative Arts Department. She maintained her apartment, juggled a full schedule of work and classes and became more confident in her parenting ability. As the year drew to a close, Linda felt ready to move on.

I'm delighted to report that Linda has moved to her home state, and is living independently with her daughter. She is working with a literacy volunteer and looking for a part time job. While Linda experienced much growth at HKNC, little does she know the education we received working with her. Future students will benefit immensely from her experience.

## Part II - The Apartment in the Mainstream Program (AIM)



Based on the information we were gathering from Linda's experience, it seemed imperative that we keep this community apartment. Although HKNC has the ILE Program, with three on-campus apartments, there are many training needs that cannot be met through this program. The apartments are in a sheltered environment within the regular residence, and one need only step out the door for any assistance. Also, the only money



students are required to budget in this program is the \$40 weekly food allowance.

After speaking with Linda's landlord, who was very supportive and even offered a reduced rent with one month's security rather than two, a plan was devised. If a student was able to use their SSI or Social Security Disability Insurance (SSDI) money, and the state counselor was willing to pay an additional monthly maintenance fee, there would be enough money to cover rent, utilities, food, laundry, transportation and miscellaneous expenses. Management was approached and, after examining the budget and looking at the lease, gave their approval.

Soon after, the AIM committee was formed, and the first planning meeting took place on April 1, 1992. We had three months before Linda moved out to prepare for the next student. The first challenge was furnishing the apartment. The Home Management Department staff made a lengthy list of furnishings and equipment that would be needed. The "Friends of Helen Keller," a group of volunteers who

raise money for student needs, came through with a very generous donation enabling us to purchase a high-rise bed, recliner chair, desk, TV and decoder, kitchen table and four chairs, telephone, TTY and a VibraCall system. It was decided that students would be responsible for supplying their own microwave oven, hot shot, toaster oven and timer - items usually recommended and purchased by the state counselor. A local carpet company donated the living room rug, and some other pieces of furniture were purchased at local garage and tag sales. However, much more was needed - dishes, kitchen equipment, linens, etc. Someone had the wonderful idea of holding a shower for "Helen's Little House."

Invitations were sent to all staff members and volunteers, and a gift registry was set up by CLC where one could check the list of needed items. A Pot Luck Luncheon was held, with several students opening the many lovely gifts for the new apartment.





The apartment, looking into the kitchen.



The apartment, living space.



Linda painted a "Bless This House" plaque as her parting gift.

A rough draft of training needs, based on Linda's experience, was presented to the AIM committee for review and discussion. Also, criteria for selection of candidates eligible for the program were established as follows:

Student plans to live independently upon leaving HKNC.

Student has adequate home management, mobility, communication and daily living skills as well as other pre-requisites for independent living.

Student has support of their case manager, state counselor, regional representative and family for participation in the program.

Student is willing to contribute part or all of SSI or SSDI monies for living expenses.

State counselor is willing to pay an additional maintenance fee if the student's money is not enough to cover expenses.

All parties are willing to commit to a minimum 6 month time frame.

Once the candidate was chosen, and while the apartment was being furnished, committee members worked on curriculum development. Meetings were held periodically for updates on progress, and individual departments were made responsible for developing certain aspects of the new curriculum. It was determined that many students could benefit from this training, not only those designated to go into the community apartment.

Following are some of the areas of curriculum that are being developed or adapted for our Independent Living Program: Looking for an Apartment/Job; Document Literacy; Health & First Aid; Emergencies - How to Handle, Who & When to Call; Money Management; Record Keeping; Dealing with Social Services; Mail; and Accessing the Community for Services and Recreation. Topics are taught

in a very concrete way using functional reading, writing and math. For example, classified ads and applications are used to teach vocabulary and assist students to understand how to go about looking for an apartment or a job. While being taught first aid, students are taken shopping to purchase items for a first aid kit which will later be used when living independently. Students are asked to make mock budgets while learning about fixed and miscellaneous expenses. Making the classes as practical and concrete as possible helps to reinforce learning.

When Linda moved out in July, the landlord painted and made necessary repairs. There was some delay with furniture delivery, but by the beginning of August a young deaf-blind man, our first official AIM student, moved into the apartment christened, "Helen's Little House." What excitement! Having a community apartment was something many staff members had dreamed about for years, and now it was finally a reality - a dream come true.



Meanwhile, as curriculum plans near completion, we continue to dream. We dream of expanding and improving this program to include several one- and two-bedroom community apartments where students can experience the realities of independent living.

## **TOUCH LOVE**

By Gelareb Asayesh

(Used courtesy of The Baltimore Sun,  
1992, Baltimore, MD)

Nancy Foster is clutching a bag of ice to her forehead. It is the end of her day at the Maryland School for the Blind where she works as a teacher's aide, and she is suffering one of her raging migraines. Nancy hasn't been sleeping well lately. Mainly, she's been worrying about Tony Hall.

It is nearly a full-time occupation for her - worrying about Tony's health, Tony's education, Tony's future. Nancy throws herself into it with fierce intensity. He deserves so much. His sheer enthusiasm

for life leaves her awe-struck. She loves to show off pictures of Tony - Tony skiing, Tony running, Tony in Halloween costume.

"He's so amazing, you know," she says. Tony is mostly deaf as well as blind, and he is Nancy's foster son. The label is a mere convenience, giving her the right to care for Tony without taking away benefits that she cannot afford to give him. If it weren't for those benefits - including a monthly stipend for his living expenses - she would legally adopt Tony. Nancy met Tony at the Maryland School for the Blind, where he is a student and where she has worked on and off since 1980. He has lived with her for five years, ever since Sept. 22, 1987. They call that their "Nancy and Tony Together Day" and celebrate by doing something fun, like bowling.

Nancy doesn't consider herself Tony's mother. After all, he is 20 and she is only 35. He is, quite simply, "my best friend," Nancy says.

They come from different backgrounds. She is white. He is black. She was born in

Cape Cod. He comes from Frederick, MD. She is the only member of her family who never finished college. Tony is considered mentally retarded by the Maryland School for the Blind, although a private evaluation placed him in the low-normal end of the IQ range.

But they came together in a place where such disparities seem trivial. At the Maryland School for the Blind, there are children whose only parents are the state; children whose smallest action is a triumph of the human spirit. It is a world apart; a place where differences like race and sex and ethnicity fade away in the face of extraordinary handicaps. It fosters either numbness or emotional intensity. It creates bonds that transcend boundaries.

At least five staff members, including Nancy, have committed to a child at the school. They don't do it out of compassion, or a grand and noble impulse, or even a need to mend the hurts of these neediest of children. They do it, like Nancy, out of slow-growing love for one particular child, one special person.



Ultimately, it is not the setting that engenders these singular loves. It is the children themselves.

Tony walks into the late afternoon hub-bub of the Holiday Spa with another deaf and blind student. Each young man rests a hand on the arm of his trainer. The plush health club has a high-tech decor accented with bright neon. Earnest men and women are pedaling hard on Lifecycles. To Tony, it is a buzz of indistinguishable sounds and darkness, but he walks without hesitation.

Tony and his friend, Charles, come over from the Maryland School for the Blind every Wednesday except when Tony has track practice. The health club is just minutes from the Taylor Avenue campus, which straddles the Baltimore City - Baltimore County line.

Today, Nancy is waiting at the club. She walks up behind Tony as he sits in the foyer and taps his shoulder. He reaches behind to feel her hair and face, trying to identify her. Their hands fly back and forth in silent communication as they sign into

each other's palms.

When Tony realizes it's Nancy, he tries to climb through a railing to hug her. They talk. Tony accompanies his signing with his own particular language made up of garbled words that only those who know him best can decipher. Tony has been largely deaf since birth, and blind since he was a toddler as a result of a congenital affliction called Stickler's syndrome.

Tony wants to know if Nancy is going to exercise. She says no, she's here to watch. The \$665 monthly stipend she receives from Social Services in Tony's home county of Frederick helps pay for Tony's sessions, but Nancy can't afford a membership for herself on her school salary. This year, she pushed Frederick County to pay for a full-time interpreter for Tony, Piel Levine, who serves as Tony's eyes as well as his translator. Now it is Piel who guides Tony from machine to machine at the spa.

Piel shadows Tony's movements with the weights, helping him lift them. Nancy swallows a familiar objection. Nobody ever

seems to think Tony can do it by himself. Nobody seems to see in him the ability and potential that she does.

Tony is sweating now. He gets a drink of water from the fountain, finding the spurt of liquid with his hand. He gropes for a position on machines he has never seen and cannot envision. He throws himself into the movements. Periodically, he invites Nancy, Piel, Charles and Charles' trainer, Gwen Pair, to feel his biceps. He is alternately gregarious and intent as he struggles to do what is asked of him.

Gwen helps Tony onto the hyperback extension machine. Tony is anchored by his ankles as he lies on his back, his upper body hanging down. He is suspended in darkness. He crosses his arms on his chest and struggles upward.

Nancy never intended to be a foster parent. She moved to Baltimore in 1979 with her husband and worked a series of odd jobs before joining the School for the Blind. By the time she met Tony, she had escaped her unhappy marriage. She had lots of friends. She had peace.



It was in 1984, and Nancy had dropped by one of the residential cottages at the school to see old friends. Inside she found pandemonium. A child had locked himself in the bathroom and had refused to come out. He had screamed and carried on. In his own good time, he came out, unchastened. Nancy saw a thin little boy who couldn't see, couldn't hear, couldn't talk and couldn't sign. Yet he had found a small way to express himself.

Who was he behind that silence? What had he to say? Later she was assigned to Tony's class. "How do you get to know someone who can't talk?" she remembers asking Tony's teacher, Julie Gaynor. "Watch," Julie said. So Nancy watched. She saw his frustration, the daily struggle of his life. She saw his passion for that life. She was touched.

Then Tony's foster parent, a cafeteria worker at the school, said she had to give him up. Her daughter had died suddenly, leaving four children. Tony would have to go to a state institution. Nancy couldn't let that happen. Not to Tony.

Social workers took Tony from his father when he was a baby after Tony's mother left her husband and two children. Since then, Tony has been in a dozen foster homes. Hers, Nancy says grimly, will be the last. Not because Tony will be 21 soon and out of state custody, but because when she decided to take him into her life she made a permanent commitment.

Tony's father, who has remarried, approves. Reginald Hall knows that Nancy can give his son what he cannot. He says he would be comfortable with Nancy's adopting Tony. He has gotten closer to Tony thanks to Nancy, who re-initiated contact that had been terminated years ago by social workers.

Nancy has a boyfriend, Steve, but he knows that Tony comes first. He gets along well with Tony, who always greets Steve with a hug. Nancy's family accepts Tony as well, though her mother struggles with the relationship. She worries that Nancy will never be able to remarry as long as she has a deaf, blind, black teen-ager living with her.

"It's kind of like, 'What does Steve think of Tony? If he has problems, you have to send Tony back to Social Services,'" Nancy says. "I say, 'Mom, Tony is not a puppy that when I get tired I'm going to give back. I made a commitment to Tony first.'"

Having him has brought consistency to Nancy's life. She takes his well-being as a sacred trust. She has learned to fight for him - an awkward role since it pits her against her employers at the school. She tries to make clear that her battles on Tony's behalf are nothing personal, but she won't give up. She has sought legal advice in her push to get Tony what he needs. The school, she says, just doesn't have enough staff who are trained in deaf-blindness.

At the Randallstown home that Nancy and Tony share with Nancy's friend Linda Woodward, Nancy tries to do what she feels the school doesn't - ask more of Tony. At home, Tony takes the trash to the curb on Wednesdays. He sets and clears the table, washes dishes and loads



and unloads the dishwasher. He does his own laundry, folding it and putting it away. He cleans the bathroom, and although sometimes he misses a spot, "It sparkles when he's done," Nancy says. He also takes care of his cat, Bubba Hall, which he received earlier this year - his first pet ever.

Each morning, he shaves himself with his electric razor, occasionally lopping off his sideburns. He has his own room with "Anthony" on the door and he makes his bed every morning. On a braille calendar, he and Nancy have marked vacations and visits to "Dad's house" in Frederick.

Nancy sees him getting a job one day - perhaps folding laundry in a hospital. She wants him to have his own home, sharing it with other deaf-blind students. She says she has to explore funding for such housing - it is in short supply. Tony still would be able to call her house home. Nancy says, "There is a forever for us."

It is a sunny afternoon, and the 96-acre campus of the School for the Blind is full of the whirring sound of lawn mowers. Students are gathering at the track where

they often run in tandem, a blind student holding on to the arm of one who can see.

In the wide, cool, linoleum-floored hallways of the buildings, an adult is occasionally seen bending over a child. Despite the institutional overtones of buff-colored walls and faintly antiseptic smells, there is a sense of self-containment about this place. Notices posted by elevators tell of births and other family events in the lives of teachers and staff. School employees often troop en masse to a ballet recital, a track meet and, occasionally, a funeral. For many of the children here, the school provides the only family they have.

As in any family, there are pettinesses and squabbles and disagreements. But there are invisible ties as well. Staff members share close friendships. Students act like siblings. Deep connections develop between children and staff. "You basically don't meet people like this in your normal walk of life," says Howard Smith, who works at the school with his wife, Pat, and has a foster daughter who attends. "It

takes a special type of person to work here. People are drawn to each other."

At the school, 325 men and women are responsible for taking care of some 200 students, five days a week, 24 hours a day. The majority of the children live on campus in dorms and cottages and go home on weekends and holidays. The children come from all over Maryland. It is not uncommon for them to come to the school at age 5 and leave at age 21 when, under the law, their right to a free public education ceases.

Once, the private, state-funded school served mostly children who were healthy apart from their blindness. Today, those children are in their neighborhood schools as part of the movement called mainstreaming. For those who remain, being blind is often the least of their difficulties. About 95 percent of the students at the school have multiple handicaps. At least 85 percent are retarded or developmentally disabled. They are so dependent that the central challenge of the school is teaching independence.



The staff teaches students how to tie their shoes and how to cross an intersection; how to brush their teeth and how to read; how to drink from a cup and how to hold a spoon. They clean them and feed them. They change their diapers. They teach them braille and they teach them about the birds and the bees. They are full-time, paid parents even though they are required to maintain professional distance.

School policy prohibits staff from socializing with students. Nevertheless, relationships such as that between Nancy Foster and Tony Hall are accepted. These are relationships that typically develop over time, says Kirk Walter, assistant superintendent at the school. It is left to the school and the staff to negotiate the gray areas that result. The dual role of parent and staff member, acknowledges Mr. Walter, can be "a little uncomfortable."

Yet school officials recognize the inevitability of strong attachments; the difficulty of maintaining distance. "Our staff have to really care about what they're doing, otherwise it's a hard way to make a

living," Mr. Walter says.

When Nancy first got to know Tony, he was notorious for his tantrums. During one burst of rage, he threw a metal object and broke an instructor's nose. His teacher, Julie Gaynor, had her own method of dealing with his rages. She had one of the aides walk him down to the school gym where Tony would run on the treadmill until he was exhausted.

The first time Nancy had to walk Tony to the gym, he pinched and pushed her. He wanted a fight. She was terrified, but ignored him. He ran until he was drenched with sweat. Afterward, Nancy took him to the bathroom and wiped him down with damp paper towels. It became a routine. The anger. The run. The calm afterward as he let Nancy make him comfortable. He would be grateful and relaxed, and he'd say, "Thank you, Nancy."

He started asking for her when it was time for the treadmill. After a while, he no longer needed that outlet. It was a process of coming to terms with himself. In sharing that process, Nancy began to know Tony.

"I guess I saw then that Tony wasn't a bad boy," Nancy remembers. "He just had a lot of emotions inside that he didn't know how to deal with."

When Tony had to have surgery to remove a tooth that had grown in his sinuses, Nancy and Julie Gaynor took turns at his bedside. Tony was covered in dried blood, tubes running into his veins. He was in pain, but he didn't cry or complain. He was 14. Nancy was helping him to the bathroom when his body revolted at the drugs in his system. He threw up all over himself and her.

Nancy recalls: "All he could say was, 'I'm sorry, Nancy. I'm sorry, Nancy.' And I said, 'It's OK. It's OK, Tony.'" She gave him a bath, his arm extended out of the tub to protect the tubes. "I got him back to bed and it was, 'Thank you, Nancy. I love you.'" At nighttime, he asked: "Going home, Nancy?"

"What do you want?" she said.

"Stay here. Stay. Please."

So Nancy lay down on a fold-up bed next to his, and she reached through the railing



of the hospital bed to hold his hand. She woke up in the morning with a numb arm and a circle of doctors staring down at her and Tony with their linked hands. "I've never had that kind of bond with another human being," Nancy says. That was December 1986. In January, after a lot of thought, she asked to become Tony's foster mother.

When school lets out for the summer, Nancy and Tony usually vacation together. It was during one such trip that Nancy had a heart attack.

It was May of 1989. They were at a folk-dance weekend in a YMCA camp in West Virginia. It was late Sunday night. Nancy and Tony left the dancing, walking into the darkness of the campground together. Tony was holding on to Nancy's arm. Then Nancy felt pain shooting in her neck, traveling down her arm, crushing her chest. She couldn't breathe. She knew she was going to black out. Everything was spinning. She could no longer feel her mouth, her body.

"God, this can't be right," she was

thinking. "I can't die because there's no one to take care of Tony."

Tony felt the tension in her arm. "Nancy, Nancy, are you OK? Are you OK?" They made it downhill to the women's bathroom, Tony supporting Nancy. Inside, Tony grabbed a woman by the arm. She couldn't understand his garbled words. Nancy whispered: "I need a doctor." Then Tony sat on the bathroom floor, propping Nancy up in front of him, holding her.

When help came, they took Tony away. She remembers being under an oxygen mask and asking over and over again, "Where's Tony?" In the week Nancy spent in the hospital, Linda Woodward and Julie Gaynor took Tony. When Nancy and Tony were reunited she cried. He yelled, clapped, hugged her. "I missed you," Tony chattered. "I love you. Nancy's heart is broken. Nancy's heart is broken. Are you better?"

Nancy answered his questions, feeling only fear. If she didn't recover fully, she would not be allowed to be a foster parent. She would lose Tony. Tony worries about

another heart attack. When Nancy has one of her frequent headaches, he wants to know if her heart hurts.

"When Nancy's heart hurt, I was sad. I cried," Tony signs. "She said, 'Ow, Ow,'" Tony remembers. "I said, 'Get up, Nancy.' I helped you." If there is another heart attack, Tony says, "I can help."

He takes Nancy's hand in his. She lifts his hand and kisses it. He repeats the gesture, then stands quietly beside her.

## **SEATTLE GROUP AIDS DEAF-BLIND PEOPLE**

By Elizabeth Weise

(Reprinted with permission from the Los Angeles Times, Los Angeles, CA)

If you can't see the numbers and you can't hear the bus driver's directions, how do you know what bus to get on?

The deaf-blind community in Seattle, Washington, came up with an answer - a deck of cards printed with numbers in large type and braille. Riders hold them up for



the driver to see which bus they want. The solution came from the Deaf-Blind Community Service Center and its deaf-blind staff. "My work is to help empower deaf-blind people. I don't complain for them, I teach them how to complain for themselves," said Mark Landreneau, a Los Angeles transplant with a degree in business. Landreneau is a case manager at the Center.

In fact, Seattle has the reputation of being a deaf-blind Mecca.

"There are five times as many deaf-blind people in L.A. as there are in Seattle, but there are no services. If I'd picked any other city in any other state I wouldn't have been able to grow in the ways I've been able to here," Landreneau said. Landreneau says deaf-blind people come here because they can do things that they can't anywhere else.

For example, there's Danny Delcambere, a cook with Usher syndrome. Usher is a genetic disorder that causes deafness and gradual blindness. Delcambere is a Louisiana transplant to Seattle. A

scholarship paid for his interpreter and support services during an internship in New Orleans with the cajun chef, Paul Prudhomme. "That never would have happened in Los Angeles," said Landreneau. "He wants to set up a small restaurant when he gets back to Seattle. He says the Cajun food here is nothing like it should be," Landreneau said.

Maria Garden can think of at least 200 deaf-blind people who have moved here since she arrived four years ago. She's a graduate of Gallaudet University in Washington, D.C., the nation's only university for the deaf. Garden, 28, is deaf and going blind from Usher. She and her deaf husband have a six-month-old son.

Like hundreds of deaf-blind people from across the country, she found work and a vibrant community in Seattle. Garden oversees a federal grant to teach people who are deaf-blind independent living skills at the Lighthouse for the Blind. "Right now, we're working on bank machines. When you can't see or hear the machine, you have to memorize all the possible

menus in the right order. So we made up a braille card that replicates the screen," Garden signed.

Theresa Smith, director of the American Sign Language School of Seattle, says the support services exist because of the strength and scrappiness of Seattle's deaf-blind community. Washington State Deaf-Blind Citizens was formally incorporated in 1982, and two years later the American Association of the Deaf-Blind held its annual convention in Seattle. More than 400 visitors from all 50 states saw what an active group of deaf-blind people could accomplish, Smith said.

Dan Mansfield is one of those movers and shakers. A founder and member of several deaf-blind organizations, he now sits on the Governor's Committee on Disability Issues and Employment. A two-month bus trip around the United States convinced Dan that Seattle was where he wanted to settle. The trip was a college graduation present from his parents. Once he got to Seattle he spent a year looking for a job.



That tenacity paid off. Mansfield, 42, who has Usher syndrome, found work as a word processor at Pacific Northwest Bell. After 12 years his eyesight began to deteriorate. His boss was under pressure to give him a pink slip, but Mansfield pushed for another chance. He and his boss appealed to Bell President Andrew Smith. Smith called together company vice presidents and told them to find Mansfield a job.

They said it was impossible, but Mansfield didn't give up. Finally, the company created a position of deaf customer services representative, a position Mansfield has held for 6 years.

## **HAND IN HAND**

by Suzie Siegel

(Reprinted with permission from the  
Tribune, Tampa, Fl)

Gray clay cakes her fingers as she shapes a model of her own hand. Clay and flesh merge.

Lesley Yando cannot hear. She sees

little. But she has no trouble feeling the wet clay. As other senses fail her, she relies on her hands to express herself in sign language and art.

She sculpts figures and hands. Her best-seller is the sign for "I love you," which combines the letters I, L and Y. "I want to show people the love in the world," she says as her husband, John, interprets her words. "I have strong hands, and I can feel everything."

Ceramic hands march across the top of an aquarium that has a mermaid inside. With billowing blond hair, the mermaid resembles its creator. Yando laughingly admits that she's the model for the school of mermaids swimming around the small apartment.

Her fingers dive down, telling the story in signs: "I'm a mermaid freak. When I was a little girl, I swam a lot. I would get mad because my mother and grandmother were always near me in the water. I would go under for a long time. I would dream I was a fish-woman."

She also created a lively old character

named Ozzie. One day she makes him a pirate; another day he may be a cowboy. Ozzie was inspired by her grandfather. She remembers him painting a funny Santa Claus, teaching her what it meant to have a sense of humor.

"It was frustrating to be in a hearing family with hearing children," she explains. Her grandfather understood, even though he never learned sign language. "He was always teasing me and making me happy."

Yando is the oldest of three daughters, and they learned sign language to communicate. She graduated from Chamberlain High School where she enjoyed art and drama classes. She says she once portrayed Helen Keller, a deaf-blind woman who became famous for her writing and speeches.

Determination and a flair for drama run through the stories Yando tells of her life. The 27-year-old was born deaf as a result of Usher syndrome. The genetic disorder also includes retinitis pigmentosa, a progressive loss of vision. She sees only up close under good light. She is considered



legally blind. At least 10,000 Americans have the disorder, which is the major cause of deaf-blindness, according to the RP Foundation Fighting Blindness, a research group with headquarters in Baltimore.

Yando can speak a few words, such as calling "baby" to 18 month old Lucas. Another baby is due next month, and she shows off something akin to a wristwatch that will vibrate whenever a monitor picks up a baby's cry.

She reads braille. With a black marker, she prints large letters that she can see on the screen of a device that magnifies words and pictures. But she never liked lip-reading even when she had better vision. "I like sign language a lot because it's very expressive," she says. "It's very dramatic to watch."

When her husband uses sign language, she holds up her hand as if to stop him. Her intent is just the opposite. She curls her hand around his moving fingers so she can feel every letter he spells. He avoids gestures too broad for her to feel in the palm of her hand.

"My husband and I have a good relationship and communicate very well," she writes. Their sisters set up their first date, and John learned the sign language alphabet beforehand. "Three weeks later, I asked her to marry me," he says. They married in 1987. John Yando, 30, works as a security guard at their Tampa apartment complex. He also fires, sands, paints and glazes her ceramics.

An unfinished Ozzie head grins on the kitchen table next to a 2-foot candleholder. Built of tiny hands, it has spaces to let loose the candlelight. As images fade, her hands recall them in clay. A bare bulb lights her work, and a lamp peers down from a shelf. Half-finished figurines and tubs of wet clay crowd the table. They eat their meals sitting on the sofa now.

When she ran out of table, work migrated to the stove. Here, a teddy bear rides a rocking horse. Pearl gray now, it will turn bright white - like the tepee next to it - after being fired to 1,600 degrees in the kiln outside.

She has worked with clay since she took

classes at the Tampa Lighthouse for the Blind five years ago. Visitors were amazed at her talent, says Sheryl Brown, rehabilitation supervisor. "She did a bust of her husband that's really uncanny."

Brown says Yando needed a way to make a living that would capitalize on her creativity and intelligence. She had learned massage therapy but had trouble finding work. Now, she massages clay.

She sold her work by word of mouth until September, when an Ybor City gallery called Changes in Artitude began stocking it. Owner Jeff Wild says he cannot imagine more adorable figures, even if her sight were perfect. "It kind of disturbs me that she isn't making what she deserves." For example, a hand-size hand goes for \$5. Some people think she uses a mold to cast the "I love you" hands because she whips out so many. "I'm just fast," she says. She can make one in 45 minutes.

She has also sold her ceramics at the John's Pass Seafood Festival in Maderia Beach. At the festival, a child pointed to an Ozzie and told his father: "That looks like



Grandpa."

A jeweler with deaf parents was delighted with the ceramic hands, and she gave Yando a silver cross that Yando now wears around her neck. She hopes to do more festivals; she enjoys the reactions of passers-by. "I want to get a lot of new ideas."

### **A PARTNERSHIP IN SUCCESS**

By Barbara Hausman, Director, Public  
Relations, HKNC

Twice a week Calvin Stallings cleans the showroom at Jimmy's Shoes on Main Street in Port Washington, NY. He removes the sporty sneakers smartly displayed in rows against the wall, dusts the glass shelves, and carefully replaces the shoes one by one. Every so often he smiles with satisfaction - and rightfully so.

Calvin is deaf-blind with multiple disabilities and, for the first time since he arrived at the Helen Keller National Center (HKNC), he's out in the community

performing a real job, enjoying a new environment. "It's a wonderful and gratifying experience for me and my employees," noted shop owner Jimmy Kallenberg. "At first, Calvin couldn't even move around in the store, now he grabs the rag and gets right down



James Schiller, (l), instructor, and Calvin Stallings, student, on the job.

to business. It's fascinating just to observe an individual grow." Calvin still needs some prompting from his job coach but he completes his tasks with confidence and pride and enjoys socializing with Kallenberg and his co-workers.

Local Long Island businesses and other institutions have agreed to provide "work experiences" for HKNC's students for the past several years. But recently,



individuals who have been referred to the Center have had more limited "life experiences" and demonstrate fewer skills.

Today, with the help of "job coaches" and a new philosophy recently introduced by HKNC staff, people with severe multiple disabilities are able to explore "real" work options and incorporate these options into future choices and plans when they return to their home communities.

Once Calvin's initial experience proved successful, HKNC's behavior modification instructor, Jim Schiller, looked around for other sites and new contacts. "Some of our students, like Calvin, need more support to investigate their potential, discover what they enjoy doing and explore their skills," said Schiller. Calvin also folds laundry at the Port Wash and Dry. With the money that he earns, Calvin often purchases luncheon snacks at an accessible deli next door - a practical and pleasurable use of his money skills.

When Polar CIC, Inc., a leading Heart Rate Monitor sales and distribution company, re-located its headquarters to



Port Washington, they contacted HKNC for help with their voluminous mailings and packaging tasks. Amy James, Polar's marketing project manager, explained that "we had worked before with other agencies in the community. I knew we had a need and I was real happy when I found HKNC." Besides the mailings that HKNC students collate and stuff for Polar customers, the shipping department brought a new job to the Center. Students are packaging inventory parts for the Polar Heart Bra Package for the company's dealers, and the service department has requested that students clean, re-assemble and test the transmitters for the heart rate monitors. "HKNC is conveniently located for Polar, their staff is very reliable, they meet our deadlines, and we are very pleased with the students' performance," said Ms. James. "As a new member of the Port Washington business community, Polar CIC, Inc. is proud to be able to contribute to a local service organization," added Polar President Burt Birnbaum.

"Businesses throughout the Long Island



Amy James (r) and Judy Cebula from Polar CIC, Inc., observe former HKNC student, Gary McFall, as he reassembles and tests their Heart Rate Monitor transmitters.

community continue to open their doors to HKNC," said Kathy Mezack, coordinator of HKNC's formalized Work Experience Program (WEP). "Our first 'in-house' customer was Merrill Lynch in Garden City. Then State Farm Insurance and the Port Washington Credit Union brought us monthly mailings." Avis' main office in Carle Place offered student, Bradley Cupit, an opportunity for a data entry work experience. In preparation, Avis supplied practice material for Bradley to set up a sample computer profile form on the computer at the Center. In tandem with a



CCTV (Closed Circuit TV) device, he could learn his new tasks during his training day at HKNC. Now, Bradley is employed part-time by Avis at their national headquarter's site, earning a competitive salary.

Once a week, three HKNC students clean the offices of Clever Devices (a digitalized sound systems company) in Glenwood Landing. Student Marcus Velazquez prices and stacks items in McCrory's and Twin Pines in Port Washington. Every Tuesday afternoon, two students work at Shareco in Baldwin (an office supply business). On Thursday afternoons, two different HKNC workers package and label materials for Shareco. Former student, Pompea Guglielmi, who trained at Clever Devices and AHRC in Freeport during her enrollment at the Center, is now permanently employed at Burger King in Commack.

The entire HKNC staff and the work experience providers in our communities share a sense of pride and enthusiasm for the unique partnership they have formed. "We celebrate each new work experience



that our students are offered - because it enhances the productive lives they strive for - and that's the bottom line," concluded Ms. Mezack.

(NOTE: If any company is interested in providing work experiences at their facilities or bring in packaging, light assembly or mailings to the Center, please contact Ms. Mezack at 944-8900, ext. 262.)

## **HELPING ADAM HAS BECOME A FAMILY AFFAIR**

By Melanie A. Hughes

(Reprinted with Permission from Town  
and Country, PA)

After their son, Adam, was born deaf and blind two years ago, and after fighting a long emotional battle to gain medical services for him, and after learning how to work the system by attending weekly overnight trips to Harrisburg, PA, Candace and Ralph Warner are making a difference. "We felt like we were groping around in a

dark room for so long," said Candace. But not any more.

Candace, Ralph and their other two children, Jill and Ralph Jr., have learned how to care for Adam after spending months researching what services he is entitled to receive. Adam's care became a family project, and now the Warners have become advocates for other families seeking support.

The family is paving the way after they were successful in gaining services for Adam other than the ones initially offered through Montgomery County office of Mental Health and Mental Retardation (MMHR).

The Warners said they were offered physical and occupational therapy for Adam until he reaches age five through MHMR. After researching benefits offered by the state, however, Adam's support now includes a county supported contract with the Pennsylvania School for the Deaf and the Overbrook School for the Blind, where Adam will receive education and training throughout his school-age years.

"If you don't read the law yourselves, no one tells you what your rights are," Candace said. "We researched what the county and state were supposed to provide for us, had several meetings and finally they agreed to do it."

Now the Warners want to be advocates for others. Ralph became versed in the law and helps other parents obtain services for their children. Ralph Jr., 15, and Jill, 13, have learned sign language, and Candace offers advice and support to mothers of deaf-blind children. For that, the entire family received the Pennsylvania Early Intervention Providers Associations' 1992 Outstanding Family Support and Advocacy Award.

The association, which represents over 100 early intervention service providers in the state, presented the Warners with their highest award because of their on-going commitment to people who might otherwise find little direction.

"Ralph and his family wanted to make a difference here and they did," said Dennis Cook, association president.



Helping other families through the bureaucratic maze surrounding disability services hasn't been easy. Ralph said most parents who have children with special needs have to find services the same way he did - without help from advocates.

According to Ralph, parents of children born with special needs are provided little more than a telephone number to an agency like the Montgomery County office of MHMR to find out what services they can receive. But too often some of the agencies aren't well versed on all entitlements for special needs children.

"What happens is, there's no one to teach parents the law and what services they are entitled to," Ralph said.

Adam has involved the Warner family in a whole new world. Presently, Ralph is president of the Special Needs Alliance of Parents (SNAP) a state-wide advocacy group. He even built a SNAP office at his business, installed a toll-free SNAP phone line and receives calls for assistance from families all over the state.

He is also president of the Pennsylvania Parents of Deaf-Blind Children, another statewide support group for parents of deaf-blind children. He serves on the Helen Keller National Center Parent Advisory Board and on the Governor's Commission for Children and Families. If that isn't enough, Ralph is co-chair of the local Montgomery County Interagency Coordinating Council. If you wish to contact SNAP call 1-800-442-4017.

## **STORY TELLER EXTRAORDINAIRE**

by Emanuel Golden

(Reprinted with permission from the NAD  
Broadcaster)

Harry Anderson, deaf-blind as a result of Usher syndrome, is a phenomenon on the scene of storytelling enjoyed by deaf people. He was encouraged to read by his mother and two older sisters, one of them deaf, in his childhood years - the first phase toward his love for telling stories.

As a child, Harry was fascinated by

watching movies, two to three times a day. There were no captions back then. He studied movements, facial expressions, and body language which became a strong cornerstone of his absorptive powers in telling stories. He also loved to watch stories narrated by students and teachers over the weekends at the Minnesota School in Faribault. Harry furthered his interest in storytelling at Gallaudet, where he was motivated by the literary skills of Robert Panara, a deaf professor.

Harry receives cassette tapes from the Congressional Library for the Blind and Physically Handicapped and uses his residual hearing to "read" (hear) books - all kinds of stories and novels. He also uses them in storytelling. He is hard of hearing and considers himself culturally deaf due to his upbringing at a deaf school and having a deaf sister.

At the annual St. Augustine Folk Festival in Florida, Harry signs stories to deaf and hearing children in American Sign Language with voice interpretation for hearing audiences.



Harry contributes a great deal of time to civic pursuits. He is chair of the advisory committee to the Florida Public Service Commission in connection with the telephone relay services for deaf, hard of hearing, speech impaired and deaf-blind users. He is a board member of the Florida Telecommunications Relay, Inc., and also served as a liaison to the Florida School for the Deaf and the Blind Board of Trustees for the Florida Association of the Deaf.

**HELEN KELLER NATIONAL CENTER  
NORTHWEST REGION,**

By Georgina Kerr

(Reprinted with permission from the  
Boeing Company)

Chuck Pyle thinks of his 26-year-old son as someone who will probably always need support. David is totally deaf, visually impaired, and developmentally disabled. Pyle, like others with a deaf-blind family member, relies heavily on the resources and referrals provided by the Helen Keller

National Center, Northwest Region.

Last year, the Boeing Good Neighbor Fund granted \$7,400 to the regional office for a computer system - their first. The office had been using a typewriter there. Now, says regional representative Cathy Kirscher, the office's computerized system helps them serve their clients better. But the computer has a larger user group: a local advocacy group, Parents and Friends Together for People With Deaf-Blindness, uses the computer to publish their quarterly newsletter. In fact, says Kirscher, the computer's large-print software was a "must" for the newsletter's former assistant editor, who is deaf and legally blind.

"Those who are both deaf and blind are a small group with a very difficult handicap," said Pyle, a human-engineering analyst in Defense and Space Group. "They lose a lot of ability to interact with their environment. My son is mentally retarded, but it's made much more severe because of his hearing and vision loss."

The Helen Keller National Center is the

only federally funded organization chartered to reach out to deaf and blind people throughout the United States. Kirscher said that the Seattle area is a mecca to deaf and blind people because of the large number of service providers here.

Kirscher knows of several Boeing families who are helped by the Center and who help each other. She calls Pyle a parent extraordinaire. "Chuck and his wife, Phyllis, are excellent advocates who tirelessly and relentlessly advocate for those who are deaf and blind. They share their knowledge and expertise with other families, especially families new to the deaf and blind arena."

## **"WORTHY OF PRAISE"**

It's a long road to your bachelor's degree, no matter who you are. For Debbie Wright of Harper Woods, Michigan, who recently received her degree in psychology from Wayne State University (WSU), Detroit, MI, that road contained a few more obstacles than most graduates face. She



was born with Usher syndrome, a condition that has left her deaf since birth and, more recently, legally blind.

"It's been a big challenge," says the 23-year old daughter of WSU journalism program director Richard Wright, "but I'm glad I took it."

Debbie's challenges began early, according to her mother, Joan. Her parents decided in the first grade to raise Debbie with oral instruction by placing her in the mainstream educational system rather than sending her to schools for the deaf. Debbie stayed with it and, with the help of a speech therapist and a teacher consultant who became like second mothers, she made it all the way to the National Honor Society at Grosse Pointe North High School. It was there that she won a Detroit Free Press writing award and came to be known as "the kid with the Wright stuff."

As one might guess from her willing acceptance of that designation, Debbie's sense of humor is a prominent part of her personality. "In fact," she jokes, "I have

both senses of humor - blind and deaf."

Before coming to Wayne State, Debbie attended Madonna University in Livonia, MI, the Helen Keller National Center and Hofstra University in New York. In 1987, she decided to move back home and attend WSU.

Apparently it's a family thing, as her mother, father and sister earned degrees from Wayne State and her brother took some classes there. Her sister, Judy, is director of computer and information services in the School of Business Administration. Getting good interpreters was a problem at first, Debbie says, but with the help of the university's Handicapper Educational Services (a unit of University Counseling Services), things have gone fairly smoothly.

Anetia Blackshear, a student assistant there who has worked with Debbie and has had a class with her, says, "In no way was she a wallflower. She puts everybody around her at ease." So much so, in fact, that Blackshear once saw Debbie standing on a street corner and tooted her car horn



Debbie Wright (center) is joined at her graduation by her family (l to r) sister Judy, mother Joan, father Dick and brother Doug.

at her as she drove by. "I completely forgot that she couldn't hear me. That's how much getting to know Debbie makes you forget about her disability."

"I hope she goes on to get her Ph.D. here at Wayne," says Marge Chmielewski, supervisor at Handicapper Educational Services. "Although Debbie communicates a little differently, she's very bright. And I think the professors can learn a lot from



her, too."

Debbie is planning to seek a master's degree, and one day hopes to work with people who are deaf and deaf-blind. She says, however, "I don't want to think about a Ph.D. just yet. One day at a time." After all, there are other things in Debbie's life besides school. For example, since January of 1991, she has worked as a student assistant for Deborah Stanifer, assistant dean for administrative affairs in the Business School.

To unwind, Debbie enjoys writing and especially, reading. Joan Wright says it's not uncommon to see her daughter leave the house carrying three or four books. "And she follows all of the plots at the same time," her mother says, "I don't know how she does it."

For all of her successes, Debbie credits her family for giving her the help and encouragement necessary to graduate. "If it weren't for them, I wouldn't be here." she says.

Also helping her stay focused is a saying which Debbie says she tries to live by

when things get tough: "Don't grieve for what you've lost- appreciate what you have."

## **TEAM IN QUEST OF CHILD'S FUTURE**

By Phyllis Stewart

(Reprinted with Permission from the Erie Times-News, Erie, PA)

A faint smile of triumph flickers around the corners of Tyler Smith's mouth. Playfully tugging at a series of eye-catching red, blue and green balls, he easily inserts them into a clear plastic cylinder.

"Good. That's good, Tyler. You did a good job on this," enthuses Sheilah Garhart, the cheerful, 40-year-old dynamo who is directing the session. "Let's get the windup train," she says giving the child a hug. For the next hour, Garhart effortlessly moves from one-piece puzzles, ring toss, Sesame Street trike, plastic airplane, miniature basketball - creating the aura of a winning football team preparing for the big game.

Garhart, an itinerant vision teacher with the Northwest Tri-County Intermediate Unit, is integrating the 18-month-old Tyler into the world of play, while at the same time working to enhance his hand-eye coordination and his ability to track - or follow - an object. One of a battery of professionals - social workers, occupational and speech therapists, a teacher of the deaf, audiologist, pediatric ophthalmologists - who are key players in Tyler's life, she has a lofty goal; to integrate the visually- and hearing-impaired child into the world around him. It is an aggressive and sophisticated effort, one in which the triumphs have been hard won.

Over the past few months, Tyler has discovered walking, has begun to master self-help skills (washing and feeding himself) and has begun to use three signs, "more", "eat," "bath," his first steps to mastering sign language. In some respects, his skills, particularly in the area of mobility, are advanced for his age. For a child who has been blind and deaf since birth, it has been a remarkable



transformation.

"He understands certain things I tell him. He understands a lot of gestures. His major delays are in communication, speech and hearing," says Kristy Smith, Tyler's mother, a slim, even-tempered woman of 34.

"He's come a long way," says Garhart, who has worked with Tyler since he was 10 months old. "Right now, my main concern is his orientation and mobility. I would like to see Tyler move from place to place safely, know where his boundaries are in the back yard and know where he's allowed and where he's not allowed."

"I can't tell you what he sees," she says, "but I think he sees more than shadows. Glasses probably sharpen and enlarge what he sees. Right now, I'm still guessing as to whether Tyler will need a cane, but just in case, we're doing some pre-cane activities such as using a Fisher-Price popper that rolls. We're using that as something that he can hold on to that would project out in front of him."

Garhart is also aggressively working with

Tyler to get the most out of his play. "Babies play. That is their life," she says. "And because he cannot see to imitate other children Tyler needs to be taught how to play, what to do with each toy, so that he knows how to socialize and play with his peers. I'd like to see him be able to play outdoors on playground and play with gym equipment."

Theirs is a singular relationship. Enthusiastic, flexible, unremitting, Garhart has expectations for Tyler and lovingly, if firmly, presses him to meet those expectations. "I expect the same from him as I would a sighted child," she says succinctly. Quick-witted, strong-willed, motivated, he in turn struggles to understand the complicated world in which he finds himself. Together, they hope to conquer that world. "That baby just loves her dearly," Kristy Smith says.

The affection is mutual and key to the relationship. "Tyler's just such a loving little boy," Garhart says smiling. "He's pleasant, he's enthusiastic. He's got his own neat little personality. He's a child

that I think about a lot, not just when I'm with him. He's just fun to work with, and I think that's a tribute to his mother, also that he is so pleasant."

Kristy Smith, Garhart says, "is an excellent parent for Tyler. She always seems to be very relaxed. Never have I ever seen her strung out enough to say 'I can't take it one more second'. She is not overprotective. She encourages him to do things. He gets a little bump, he falls down. This is going to happen. This is the way he's going to learn. She's letting him explore. Normally, you have to kind of tell parents, 'Back off.' I think she knows when to back off and when not to."

Tyler continues his childhood explorations according to a carefully drawn plan. He receives regular occupational and speech therapy and has twice weekly sessions with Garhart and with a teacher of the deaf. Within a few weeks, the family, including Tyler's father, Loren, his older brother, Steven, three and a half, and his grandmother, will resume weekly sign language classes.



It is just such early intervention which Tyler has been receiving for the past nine months that specialists agree is critical to the development of a deaf-blind child.

Also critical is parent education. Both Kristy Smith and Steven are involved in all of Tyler's classes and, says Garhart, much of her time is spent "showing Kristy how to do things with Tyler. Blind children need to be shown almost everything. Don't open a can of orange juice and put it in a glass. Take an orange, cut it up, squeeze it in front of him so that he sees that orange juice comes from oranges. Blind children need exposure to many, many things. And the more exposure he gets, the more adaptable he'll be in his environment."

For the newly self-confident Kristy Smith, the past several months have also marked an unmistakable transformation. "There's a goal in her life now. She has something to focus her energies on," says Loren "Butch" Smith, a kind, soft-spoken man of 43, who is plant engineering manager at the Parker White Division of PHB Inc.

"Tyler was the means for her to find something to focus on." In fact, she has made the rehabilitation of her son a personal crusade.

Driven to secure aggressive intervention for their son, both Smiths have zealously waded into their roles as teachers and advocates for the handicapped. They were quick to educate themselves in the intricacies of the law, particularly Act 212, the Pennsylvania Regulation for Early Intervention Services, which details what intervention Tyler is entitled to under the law. Until he is 3, the cost of those services (including evaluations, therapy, materials, books and transportation) will be paid for by the Department of Welfare. The state Department of Education will assume financial coverage from 3 to 21. Income is no criterion for services under Act 212.

They have also learned to implement the techniques of Tyler's regimen into their daily routine. Yet, even with the involvement of an extended family and a large support network, assuming a place on

the front lines of their child's battle for assimilation has not been easy.

"Honestly, it's very difficult. But that's just the way it's going to be, and we've been adapting to it," says Kristy Smith matter-of-factly. "You get tired. You get fed up when you're fighting for the services Tyler is entitled to. You get frustrated. But we're hanging in there. I try not to even think. Every day I just look at my schedule to see what I've got to do."

None of it, however, really seems to faze her, not even the fact that Tyler prefers to remain on familiar, safe territory. "Tyler likes his house. Tyler likes to be home," she says as she sits barefoot in tan shorts and a yellow sweatshirt on the floor of the living room in the family's home on a quiet, tree-lined street. "So in order to go anywhere, you don't go for a long time. And he's not communicating well enough that you can tell him, 'Wait, we're going to be done in five minutes.' He does not understand any of that. I'm really hoping by fall this child's going to communicate.



That's the hardest part. He does, in a way, but it's so difficult. When a child verbally doesn't tell you something, it's tough."

Tyler would, in fact, prefer not to stray into the dangerous and unfamiliar territory of the outdoors at all. On one overcast, humid July day, as he ventures out into his backyard, the glare is clearly more than he has bargained for. Behind his pale blue glasses, his brown eyes are tightly closed, indicating, Garhart says, that he may be light sensitive.

"I don't know if it's the sun or, as Sheilah says, it's just a big world out there. Some days you take him out and he looks up in that sky and he just screams until you take him back in the house," Kristy Smith says.

Despite the demanding regimen that is by necessity the hallmark of her days ("Anytime Tyler's playing, you're actually working with him"), Kristy Smith says she has learned to enjoy her son. "He's a challenge, but it's a different type of enjoyment than Steven," she says. "You can't just let him be a baby. And that's

hard. Tyler will go off by himself, but you can't let him. If Tyler had his way, he'd be off by himself 24 hours a day. He will go into his own little world."

She is quick to point out, though, that along with the challenges come great rewards. "The accomplishment! You work week after week on something and all of a sudden he does it."

Another key figure in Tyler's development is his father, who relishes the evening and weekends he spends with his sons. "Tyler has made everything else in my life seem small because of the effort that we have to put forth to make his life better. Everything else around here is secondary," Loren Smith says with a quiet, measured sincerity.

"When I leave work, I come home here and, boy, the effort is toward Tyler and Stevie," he adds. "It was hard for a while to adjust. I think it would have been hard for anybody. But after a while and you see the effects. Holy cow! Tyler can sign now. Tyler knows how to stack toys together. He initiates little chase games, hide and

seek games. I guess, inside, I really didn't expect it all that quick.

Essential to Tyler's continued progress is communication, and the campaign to develop his skills in that area is full speed ahead. Twice a week, Barbara Duchini, a teacher of the deaf at the Dr. Gertrude A. Barber Center spends 60 to 90 minutes working with Tyler and his mother on a series of exercises designed to "establish a language base" for the child. Last summer, Tyler began to wear an auditory trainer, similar to a hearing aid. It is designed to block out background sounds and appears to be more effective than the aid he wears in his left ear.

"In an effort to enhance that communication, stimulate some hearing and develop an awareness of sound, Duchini, working with a variety of devices including cassette tapes, assorted brightly colored toys and a large yellow hand puppet named "George," bombards Tyler with an array of sounds from music to the honk of a horn and bang of a drum. Their sessions, often conducted in tandem with



a Barber Center speech therapist, are, Duchini says, "an ongoing study; an experimentation, to determine what he does hear."

Complicating the task is Tyler's blindness. "For a child who is deaf and has vision, you can show them a manual communication system (sign language). For Tyler, you don't always know if he sees a sign," Duchini says. "Is he understanding, or does he think we're just grabbing his hands? So much of it is a guessing game."

The goals that preoccupy Duchini, who brings a calmness and purpose to her task, are colored by Tyler's special circumstances. "Short-term, I'm just hoping that his communication continues," she says. "I want him to keep adding to his vocabulary; to understand more and more of what we say; to give more back to us; to start making some choices about the things he wants ... naming desired objects."

"He's doing a lot of things vocally all of a sudden that have really surprised me. He's imitating many of the sounds that we're making and I think the new auditory

training seems to be making a lot of difference. We'd never expect him to imitate words at this point. But we try everything and see where it leads."

Yet, whatever setbacks they may yet encounter, Duchini is confident of the ultimate long-term success of the blitzkrieg. "I do think that he is intelligent, he's curious, and he has a lot of potential," she says. "It's just our challenge to interpret things to him so they make sense, explain things to him so he understands."

"Kids like Tyler deserve a chance to show what they can do," says Ronald Price, M.D. of Cleveland, OH, one of the pediatric ophthalmologists who has examined Tyler. Even though specialists cannot yet say with certainty what he can see (his age and deafness make him difficult to evaluate), they agree that Tyler appears to show visual attention to a light or toy and that he seems to try and follow an object.

And both Price and pediatrician-ophthalmologist Nicholas Sala, M.D. of Erie, PA, who examined Tyler last month, refuse to put a label on his impairment. "If

I say he is severely impaired, it marks him. People will relate to him differently," Sala says. "No one should pin labels on children like Tyler," emphasizes Price. "No one should hold them back or prevent them from achieving their potential."

Cautiously optimistic that Tyler's skills will continue to develop, the Smiths, tireless advocates of mainstreaming their son, are already looking ahead to his school years.

"The scary part is putting him in school with typical kids. I just don't know how I could hold myself back if somebody made fun of my child. I might have to go berserk at the time." Kristy Smith says with a laugh. A pause. "That is my biggest fear," she adds quietly, "that he is not going to be accepted in this community."

## **HERE AND THERE**

The seventeenth Annual Open Convention of the American Association of the Deaf-Blind will be held June 12-18, 1993, on the modern campus of California, State



University at Northridge (CSUN), California. A busy schedule of workshops, tours, and social events has been planned, including an awards banquet and an all-day outing to Disneyland.

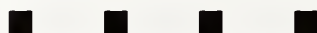
For further information, or to obtain applications, contact AADB's home office: 814 Thayer Avenue, Silver Spring, MD 20910-4500: Tel: (301) 588-6545 (TDD only).



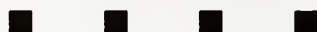
A national DIRECTORY OF AGENCIES AND ORGANIZATIONS SERVING INDIVIDUALS WHO ARE DEAF-BLIND is now available from the Helen Keller National Center. The directory covers over 250 public and private agencies which provide services to deaf-blind persons in the United States. Bound in a loose-leaf notebook format, convenient for deleting or updating material, the directory costs \$25.00 prepaid, which includes shipping and handling.

To order, send check or money order to: Helen Keller National Center, 111 Middle

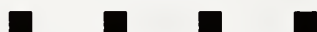
Neck Road, Sands Point, NY 11050. For information, call: Allison Burrows, (516) 944-8900.



Handicapped Plus, 1810 32nd Place, NE, No. 6, Salem, Oregon, 97303, has braille calendars for sale at \$1.25 each, or, if 12 are ordered, they cost \$1.00 each. The size of the calendar is 6" x 11" with a page for each month.



As a public service, National Braille Press, Inc., has compiled a list of braille transcription services in the United States. The information was collected in May, 1992. For a free braille copy, contact: National Braille Press, Inc., 88 St. Stephen Street, Boston, MA 02115; Tel: (617) 266-6160.

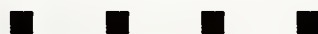


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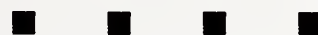
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Body Shop Cosmetics is an international cosmetics company that produces and sells more than 350 naturally-based, ecologically friendly skin and hair preparations. The company's catalog may be obtained in braille by calling (800) 541-2535.



AT&T has announced the availability of newly designed braille AT&T calling cards. Promotional materials are being provided in both braille and print. The card contains the AT&T label, along with the user's permanent number. To order, or to obtain more information, call AT&T at (800) 942-6021.





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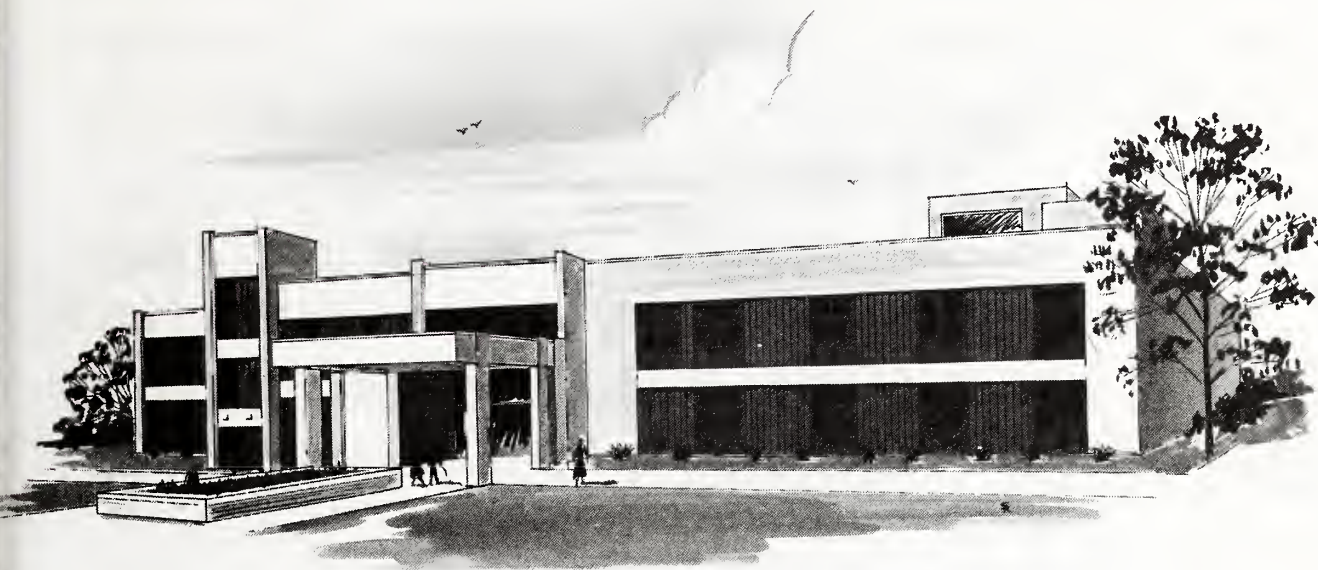
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**EDITORIAL**  
**A SPECIAL BOOK**  
**ABOUT SPECIAL PEOPLE**

by Robert J. Smithdas, LHD, Litt.D., LHD

Literature about deaf-blindness and how to overcome the basic, unique problems of independent living for deaf-blind people is notably sparse when compared to the volumes of information written about other groups of the disabled. When a dedicated professional worker turns author and writes a book describing years of experience assisting deaf-blind people to adjust to community life, then it is a major contribution to our knowledge and understanding of the methods and techniques that can be used with beneficial results.

Such a book is the exciting and important new publication, INDEPENDENCE WITHOUT SIGHT OR SOUND: SUGGESTIONS FOR PRACTITIONERS

WORKING WITH DEAF-BLIND ADULTS by Dona Sauerburger, and published by the American Foundation for the Blind. In this eminently readable book, Ms. Sauerburger recounts her rich experiences in a very personal, down-to-earth and practical way, illustrated with many examples of real-life problems and situations. This approach makes the book an ideal reference and guide for families, interpreters, educators, and deaf-blind persons themselves, as well as for professional rehabilitation workers.

Dona Sauerburger has had more than twenty years experience working with deaf-blind youths and adults in the areas of orientation and mobility and independent living. She has worked with individuals from widely different educational and social backgrounds, and discusses various methods, techniques, aids and devices that can be used for solving specific problems or meeting individual needs. Pervading the book's pages is the author's sincerity and

desire to help those without sight and hearing to attain the highest quality of life possible.

INDEPENDENCE WITHOUT SIGHT OR SOUND is available in either print or braille editions for \$35.00. Orders should be sent to: American Foundation for the Blind, c/o American Book Center, Brooklyn Navy Yard, Building No.3, Brooklyn, NY 11205 or call (718) 852-9873.

### **FIELD NOTES**

by Dennis Brady, Assistant Director,  
Field Services, HKNC

This past spring and summer I did quite a bit of traveling. I attended the American Association of the Deaf-Blind (AADB) Convention held in Los Angeles. Several people I met recognized my name from this column. It was nice to meet some avid NAT-CENT NEWS readers.

I also attended the American Deafness



and Rehabilitation Association (ADARA) Conference in San Francisco and the Self Help for Hard of Hearing Persons (SHHH) Convention in San Diego. At both of these meetings I spoke with many people who were interested in knowing more about people who are deaf-blind. I think this is terrific. The more people get to know one another, the less likely there will be barriers between them. I encouraged the deaf-blind people who were attending the ADARA conference and the SHHH convention to get more involved. People who are deaf-blind are best able to educate others concerning the deaf-blind community and the issues it faces.

In the last issue of NAT-CENT NEWS there was an article about the recent changes in the HKNC Act. Congress has also passed The Rehabilitation Act Amendments of 1992. Some very important changes have occurred with this new law. There is now an assumption that

people with disabilities can work! "A person with a disability, regardless of the severity of the disability, can achieve employment and other rehabilitation goals, if the appropriate services and supports are made available." If any of you have previously applied for services from your state vocational rehabilitation agency but were denied, I encourage you to consider re-applying. These new amendments are clearly in your favor. Also, the voc. rehab. agencies now recognize that deaf-blindness is a single condition. Previously, a deaf-blind person was considered primarily deaf or blind and there was no clear record of how many deaf-blind people were being served by state agencies. The situation is very different now. There were many other changes made with these amendments. They have tried to emphasize the positive capabilities of individuals and expand the opportunities within Supported Employment. If you think

you might be eligible for services from your state agency, call them or call HKNC.

My final update is about the Technical Assistance Center at HKNC (HKNC-TAC). This summer they provided two, three-day workshops to approximately 30 "622 Coordinators." A 622 Coordinator is responsible for the federal money that is given to a state for the education of students with deaf-blindness. The workshops focused on transition services but they also gave the coordinators an opportunity to see the evaluation/training program and a chance to meet with the staff and students.

### **BRAD CUPIT ACHIEVES SUCCESS**

(Reprinted with permission of the  
Concordia Sentinel, Ferriday-Vidalia, LA )

Born deaf and legally blind with a rare eye disease called Leber's II, which was diagnosed when he was eight years old,



Bradley Cupit has achieved remarkable success in his lifetime. "Brad's come a long way in 23 years," explained Mary Cupit, Bradley's aunt who has been a loving figure and strong advocate for her nephew all these years.

It wasn't easy. As a child, Brad had terrible temper tantrums. "Every day after work I'd change my clothes and the fight would start," said Ms. Cupit. "He wouldn't feed himself and everything went on the floor. Brad's parents both worked and fortunately, his day care teacher reinforced the pattern of discipline we were following at home." For three years an itinerant teacher from the Parent Pupil Educational Program (PPEP) at the Louisiana School for the Deaf worked with the family at home. Sally Martin and Dine Bordelon were cited as key people in Brad's early support system.

Like his parents before him, Brad graduated from the LA School for the Deaf

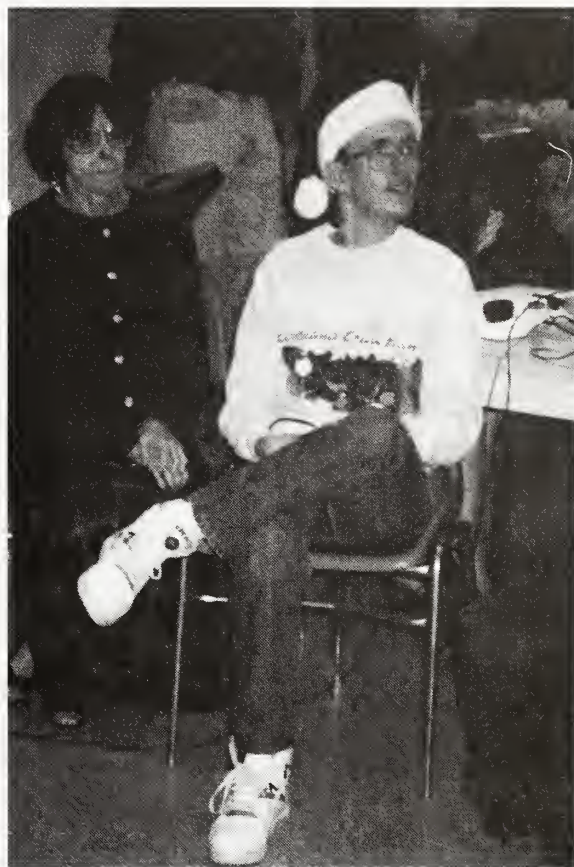
and returned for a post-graduate program. During three summers, he participated in the mayor's Summer Youth Work Program tackling a host of different jobs.

Brad, the son of Donald and Leora Cupit of Baton Rouge, Louisiana, was selected for the poster of the 1993 Helen Keller Deaf-Blind Awareness Week. This campaign for awareness of deaf-blindness is sponsored by the Helen Keller National Center for Deaf-Blind Youths and Adults. This year it focused on accessibility in the workplace and employment opportunities for people who are deaf-blind

In January 1992, Brad entered the Helen Keller National Center's (HKNC) rehabilitation training program in Sands Point, NY, to refine and expand his independent living skills. During the one and a half years he was there, he explored several "real" work options and found that he preferred data entry work. He practiced inputting information on a sample Avis

customer profile form using a computer, a CCTV (closed circuit television which magnifies print), and VISTA, a special enlarged text system.

After his work experience at Avis' national headquarters in Garden City, NY, proved so successful, he was offered employment and worked two days a week earning a competitive salary. He moved from the HKNC Residence on campus to an apartment rented by the Center in the local town, where he managed his own household-cooking,



Volunteer, Jinny Mohn and Brad  
enjoy the holiday festivities at HKNC.



shopping, budgeting and more. Several aids and devices enabled him to communicate with others. His VibraCall, a wireless paging system, transmitted basic lifeline information through a pocket-sized receiver he wore on his belt. Different vibrations informed him of the telephone ring, doorbell or smoke alarm. He used a TTY with a large print read-out to call friends and family.

In April, Brad returned home and began a four month internship for a government position in the State Group Benefits Department in Baton Rouge. If he meets their production rates, he will become a full-time employee. He also met with the Community Independent Living Services staff who will assist him with finding an apartment.

"It's been a long, hard struggle, and without God's love, a strong faith and the help and support of so many people sprinkled in over the years, it couldn't have

happened," concludes Ms. Cupit. "There are many chapters in the book of life and HKNC ended one chapter for Brad. Now he's beginning a new one - accepting full responsibility for himself and joining the world of work as an adult."

## **HANDICAPS COULDN'T STOP HER EDUCATION**

by Jim Parks

(Reprinted with permission of The News  
Journal, Wilmington, DE)

Krista Caudill blushes when asked about her boyfriend, giggles while comparing teachers with a friend and turns serious about the subject of college applications. The 18 year old Wilmington Friends School student is like any high school senior, except in one respect: She can neither see, hear nor speak.

She has kept pace since entering the private school in Alapocas in the second

grade. Her grades are generally B's, and teachers describe her as an eager learner. She said she is looking forward to college - applications are pending at 3 colleges, one of them a school for the deaf - and a career as a counselor.

Caudill admits to some apprehension as graduation approaches. "I'm sad to know that it will end soon," she said. "I have many friends and I wish we could all stay together."

"Krista is just like any of us. The only difference is that when she talks, we hear Gwen's voice," said Mandy Bartoshesky, one of her friends.

Gwen Palmore, 41, has been Caudill's interpreter for about 3 years. They converse through a combination of finger-spelling and sign language. Fingerspelling is a technique in which words are spelled out on the palm of the hand.

When Caudill converses, her arms and fingers move at a rapid pace, even faster



when she's excited or angry. It is possible to make signs as expressive as the tone of a voice, she said.

Bartoshesky is one of several Friends' students who have learned to communicate with Caudill directly. When she was in the fourth grade, the entire class learned to sign. Bartoshesky, who didn't come to the school until the ninth grade, picked it up on her own as an accommodation to a new friend.

That accommodation was one of the few Caudill said she experienced. "They treat me like any other student, and that's the way I want it to be," she said. Caudill gets around with the aid of a collapsible walking stick. Other students brush by in the hallways without taking any particular notice of her.

Since the beginning, she has had a full schedule of regular classes, has been expected to complete research papers and other assignments, and has engaged in

most extracurricular activities. "The only break I get is that sometimes a teacher will give me a little extra time to complete a test if I need it," she said.

In middle school she was told she could waive the foreign language requirement. But she found a Spanish textbook in braille. Her interpreter didn't speak that language, and Caudill had to learn without the benefit of the oral classroom component. Caudill knows some Spanish and said she enjoys using it with a Hispanic friend.

"Yes, I am a fighter," she said. "If they say I can't do it, that doesn't stop me from trying to do it. I like to do for myself. If I really can't do it, I find out. But most things I find that I can do."

Advances in computer technology have given her a boost. "I am fascinated by computers. With computers we can communicate even better," she said.

In class she uses a lap model keyboard, which can be attached to a desktop printer

that also produces a braille display. Using the equipment, Caudill can carry on a conversation with a sighted person at a speed slightly slower than through an interpreter. The device also can be hooked to a telephone.

She's hoping for further miniaturization of her equipment. Her daily commute between school and home in Westmoreland requires her to carry, in addition to her books, several pounds of electronic equipment in a back pack slung over her slender shoulders.

Having an interpreter along in social situations can prove awkward, she said, especially for a teenager. But she is assured by the confidentiality dictated by the ethics of interpreting and she said she trusts Palmore, who is provided to Caudill by the public school system.

"I know that Gwen won't, and can't, tell anybody what we talk about. But not all my friends are always comfortable with



that," Caudill said.

"Krista's very good at keeping secrets herself," Bartoshesky said.

## **WORK PROGRAM HELPS DEAF-BLIND YOUTH WITH LIFE SKILLS**

by Leann Eckroth

(Reprinted with permission of The Daily  
Journal, Devils Lake, ND)

Like most boys his age, Casey Ridley is a car fanatic. Upon the arrival of any newcomer (including reporters), the 19-year-old zips to the window to size-up the make and color of the car. In fact, he knows every staff member's vehicle at the North Dakota School for the Deaf (NDSD). He is also known, most undisputedly, as the Nintendo Champion of his dorm at NDSD.

Casey, as you already have guessed, is deaf. But he also faces the additional

challenge of being legally blind and mentally disabled. These barriers are not exactly ideal for finding employment.

But Casey is working. Through a work experience program at NDSD, Casey is a stocker at Super Pumper in Devils Lake. He stocks the cooler, fills the ice dispenser, cleans tables, washes dishes, prices candy and takes out the garbage.

According to his advisor/special needs instructor, Beth Michel-Evanson, an obvious transformation has occurred in Casey's behavior since he started the program more than one year ago.

"We wanted to give him some different kinds of work experience. It's a big social experience in the community," she said. It's been wonderful. He has grown socially. He has always been kind of shy. He feels real good. It has boosted his self esteem. He looks forward to going to work. He practices saying good morning to the people here.

Michel-Evanson said she and Casey have developed a special rapport in the past 10 years, but he has difficulty relating to others. She stresses that Casey's involvement socially would not have been possible without the cooperation and patience of the staff at Super Pumper.

Lynette Hass, manager at Super Pumper, has been very pleased with the progress of Casey's work. "He does real good. He keeps busy. He does excellent work. The candy packages are premarked on the side of the box and he copies them."

Hass said Casey is also quick to take initiative - looking for tables to wipe and other things. When something is done incorrectly, she said they "just talk" and she shows him the right way.

Casey's social skills are evolving, said Hass. "He likes to ask the other boys about what kind of shavers they use. It's a kind of bonding thing."



Hass admits there was initially a problem with Casey's attention span, but says that has been worked through and he understands he must complete any assigned task without distraction. "He's come a long way," said Haas. "He even stays once a week and purchases his lunch."

In two years, Casey's studies at NDSD will end. To further gauge his ability levels, he attended the Helen Keller National Center in Sands Point, New York, this past summer. The Center is especially designed for deaf-blind individuals. Michel-Evanson said the Center will help NDSD to determine which direction to take in Casey's studies for the next two years.

## **THE DEAF-BLIND COMMUNITY: IN TOUCH**

(Reprinted with permission of  
The NJRID MEDIATOR)

Last spring the MEDIATOR invited two members of the deaf-blind community to share their perceptions of their lives and experiences working with interpreters. Melba Collins is a lifelong Trenton, NJ, resident. Winnie Tunison is currently attending the Helen Keller National Center. The interviews were conducted and translated by Jan Niedermaier. Interpreting assistance was provided by Tom Gradnauer, John Tunison and Glenda McCary-Moos. The MEDIATOR would like to express its appreciation to Dr. Galloway and NJ/MKSD for allowing us to meet with both women at a Deaf Pride Month event in March.

Melba Collins: I graduated from the New Jersey School for the Deaf (NJSD) in

1932. I started school at the age of five in 1920. Back then we were at the old school on Hamilton Avenue. It had once been a home for Civil War orphans. I was born deaf into a hearing family. My major was sewing. I hated it! It was such a pain trying to thread that tiny needle! But I persevered. As a child my vision was blurry and I lost my sight totally when I was in my fifties. I'm now seventy-nine years old.

I met my deaf husband at NJSD. We married and have one daughter, who is hearing and can see. I live with her now but until recently I kept my own apartment where I cooked and cleaned and did everything myself. I've always been very independent. I've never asked other people to do things for me. Instead, I've always prayed and asked God's help to learn what I've needed to know and do.

When I lost my sight and could no longer enjoy TV, my mother (who lived to



be 105) taught me to crochet. At first, it was frustrating. I couldn't see to follow the directions so I asked God's help and taught myself bit by bit to make many things. My first project was a small toy dog. Since then, I've made sweater vests and suits, blankets and afghans, shawls, and decorations for my home and as gifts for friends.

I learned to cook by trial and error. I arrange objects and then determine by taste what each is. I have to be careful to put each back in its proper place so I don't mix them up. I experiment with different dishes and ask my husband to try them. Sometimes the results are a success and sometimes thumbs-down - and I try again. I remember the first time I tried making cinnamon buns. Boy, were they ever a hit!

Often my daughter interprets for me. Once in a while I have a certified interpreter. It's difficult for me to follow

many of the new signs. People go so fast! I like the old signs best. Sometimes I have several interpreters at church where, after the service, we have a social hour. I enjoy talking with so many people - even if my arms do tire from holding them up so long. Recently I attended a deaf-blind banquet. That was wonderful!

I'm grateful when people have the patience to communicate with us deaf-blind folks. I'd love to have more opportunities to meet people and to attend more interpreted events. I love my life with my Lord and my family and friends. I'm happy and busy all the time, not lonely or sad or bitter. I love you all. God bless you!

Winnie Tunison: I graduated from NJSD in 1966. It was not until ten years later that I began to notice problems with my vision. In 1980, I realized I could no longer read print - even enlarged. I lost my remaining vision five years ago.

I've been married to John, who is deaf, for twenty-five years. We have two daughters who are hearing and sighted. The elder is in college studying to become an interpreter for deaf and deaf-blind people. Our younger daughter will enter college this fall to study physics.

At HKNC, I'm learning independent living skills so that I can eventually go to work. With my daughters grown, I don't want to just sit at home. I have so much to learn and so much to teach others about deaf-blind people. I'm very interested in teaching other deaf-blind people to read braille, and in helping interpreters learn to work more effectively with the deaf-blind community.

At HKNC, I chair the Town Hall meetings where students discuss issues and plan events. A deaf counselor there, Loretta, is my favorite interpreter for these meetings. She makes sure to convey all the visual cues that help me determine the



mood of the group as the meeting progresses.

For example, one friend in the program had been without CCTV (a system that enlarges regular print) for three days. She slapped her arms down on her lap to show her frustration. When Loretta mirrored her gesture, it helped me connect emotionally with my friend's plight. I knew just how she felt and I could really empathize. This is so much more than simply receiving the signs: ME NO CCTV THREE-DAYS into my hands. What are signs without the emotional and relational context? Flat and empty.

It is puzzling that interpreters who are very animated and expressive when interpreting for deaf people suddenly become flat, bland and expressionless when interpreting for deaf-blind people. We need to know the emotional tone of what's being said/signed and the audience's response in order to be

connected to what's going on around us and to participate fully in it. Even though we no longer see with our eyes, our minds are hungry for pictures of our surroundings and the characters who inhabit them - not a flat narration, but a living interaction.

Many deaf people are natural interpreters for deaf-blind people because we share a common visual frame of reference. Not all deaf people want to or can be interpreters, nor do all deaf-blind people want or have the patience to teach others how to interpret for them.

But, in general, deaf people will be more sensitive to conveying visual cues - such as the person signing is storming angrily around the front of the room - or the audience's reaction to the speaker. Deaf people are quicker to pick up on the deaf-blind person's feedback - whether they're enjoying or confused by the interpretation. It is really aggravating and insulting to constantly be asked whether one

understands the interpreter. Deaf-blind interpreting seems ideally suited to the talents of deaf relay interpreters.

Interpreters need to be socialized into the deaf-blind community in exactly the same way that they're introduced to the deaf community - through attendance at deaf-blind clubs where they're encouraged to seek out those deaf-blind folks who are interested in mentoring interpreters. Integration should begin with interpreters' earliest training to foster a level of comfort and confidence that will enable them to interact successfully with deaf-blind people. Formal workshops can then teach specific skills, building on the foundation of students' basic familiarity with the community.

There is so much to deaf-blind interpreting that it would take days to cover it all. Here are just a few basic tips to enhance everyone's physical comfort:

- Build your upper body strength so as



to build your stamina for the physical demands of deaf-blind interpreting.

- Avoid wearing jewelry - even a wedding band can be an irritant during prolonged tactual contact.

- If you tend to have rough or dry skin, use an unscented hand lotion. Otherwise, both you and those for whom you interpret could wind up with painful rashes.

- Because deaf-blind interpreting requires close physical contact, be extra careful to monitor your personal grooming. Avoid strong smelling soaps, shampoos, deodorants and perfumes that can send a deaf-blind person reeling dizzily after even a short time. What may smell nice in passing can be a real headache up close and personal.

Finally, make sure you position yourself so as to be able to see the deaf-blind person's face. You will get vital feedback about the situation and your interpretation by keeping watch.

EDITOR'S NOTE: Mrs. Tunison recently appeared, along with Ilene Meyer, social worker at HKNC, on a local New York cable TV station during which she describes the psychological impact of the loss of vision for someone who has functioned as a deaf person. This 28-minute video will be available in October from the Public Relations Department at HKNC. To order, call (516) 944-8900 ext 325.

## **WORKING WITH THE DEAF-BLIND COMMUNITY**

by Diane Goldberg Weiss, MA, CSC  
(Reprinted with permission of the NJRID  
MEDIATOR)

The deaf-blind community is made up of people with varying communication needs. The first group is composed of people who are blind or legally blind and later lose their hearing. The second group is made up of

those who are deaf or hard-of-hearing first and then experience a loss of vision. The third group is comprised of those who are adventitiously deaf-blind having been hearing-sighted for a significant part of their lives. The fourth group is multi-handicapped deaf-blind - people who are born with multiple involvements. Each group has its own characteristics.

I have had the pleasure and privilege of knowing this community from working with its members. As the Deaf-Blind Specialist for the Commission for the Blind and Visually Impaired, my job is two-fold: to provide vocational rehabilitation services to deaf-blind individuals who are clients of our agency, and to provide information to the community at large to make access to established services easier. As a former interpreter/instructor at the Helen Keller National Center, I had the opportunity to meet and work with deaf-blind people from all over the country. Throughout these



fifteen years of contact, individuals who are deaf-blind have taught me many ways that make it easier for them to receive interpreted information. I would like to share some of their ideas with you.

There are some differences in providing interpreting services to members of this group as opposed to members of the deaf-sighted community. Members of the deaf-blind community will use one of three modalities for listening: auditory, visual, or tactile.

**Auditory:** A visually impaired or blind person who is losing their hearing may continue to depend on auditory listening during the adjustment process. They may rely on assistive listening devices. While "voicing," it may be necessary to speak into a microphone or to speak close to their ear. Explaining to the person about things that are presented visually is also important. In addition to producing an English message, you will want to consider

adding English where there is none. For example, the speaker says, "These are the books I find most useful," and holds them up for viewing. Here, the interpreter can add the names of the books. It is important to identify each speaker as they begin: "Mr. X says...." This allows the visually impaired listener access to who is saying what to whom.

Visual: A deaf person who is legally blind or who has a progressive vision loss will continue to listen visually, but with modifications. If English is the preferred language, it can be produced by typing on a TTY with a large visual display. They can watch the screen and read the information.

Your listener's preference might be for ASL. They may be partially sighted or may have no usable vision. For a listener with Usher syndrome you will need to sign in a small space near your face. The pace will need to be a little bit slower than usual and you will need to be aware of your own

"use of space" limitations. If there is more than one listener with Usher syndrome, the listeners will have to decide on common turn-taking techniques. This will allow each one sufficient time to "find" the speaker without missing their remarks.

Tactile: If you have a tactile listener, you will need to add to signs with non-manual markers. For example, the phrase "I don't understand." In ASL you could sign UNDERSTAND and shake your head from side to side to indicate negation. With a tactile listener it will be necessary to sign NOT and UNDERSTAND. When using signs that have contact with your body, it is important to actually touch yourself. For example, with the sign glossed as HAVE (possess) there is physical contact made between the tips of your fingers and your chest. Some signers are inhibited about touching themselves and this adds difficulty to tactile listening.

There are at least three ways to convey



laughter to a tactile listener: you can indicate who is laughing and sign LAUGH; you can indicate who is laughing and use the "HaHa" sign; or you yourself can laugh (with low voice). The tactile listener can feel the laughter.

Although a person may no longer have usable vision, if he was sighted at one time there will most likely be visual memory. With nonverbal techniques, time pauses and speaker characterizations can be supplied. For example, to indicate a speaker is evaluating someone's comment, you can lightly stroke your chin with your thumb and index finger.

Someone who is deaf and blind can listen tactilely. With Print-on-Palm, the interpreter uses their index finger and prints in capital letters on the listener's palm. Using the manual alphabet, an interpreter can spell letter by letter into the listener's hand. If sign language is preferred, an interpreter can use it and the

listener will put their hands over the interpreter's to understand what is being communicated.

A person with Usher syndrome who has had an oral education may still be able to depend quite a bit on oral interpreting, if this was a preferred mode prior to field restriction. Another oral technique is the Tadoma method, a form of tactile lip reading. Placing one or two hands on parts of the interpreter's face, the person who is deaf-blind can understand spoken information by touch. Using this method, the interpreter vocalizes the same spoken message presented by a speaker.

Environmental Factors: Environment is extremely important. The goal is to maximize visual and physical comfort and to minimize fatigue for both the listener and the interpreter. The need for good lighting and a non-distracting background is similar to that of deaf-sighted people. Lighting needs should be discussed with

each listener, as each person may have different preferences. Sometimes a portable light may be needed for movies or classroom activities where the lights must be dimmed or extinguished. The speaker or conference planner should be alerted to this need to ensure adequate preparation.

There are generally four positions used for tactile listening: side by side (interpreter using right hand to communicate, person listening with their left hand); side by side (interpreter using left hand to communicate, person listening with their right hand); side by side (facing opposite directions); and sitting around a table. Prior to an interpreting assignment, the interpreter and listener should try out several of these positions to discover which is most comfortable for both.

Different settings will impose a variety of guiding needs when you are interpreting for a visually impaired person. Some of these may include: a revolving door, stairs,



an escalator, a narrow pathway, or a bumpy road. There are two excellent resources for information about guiding: mobility specialists (from an agency serving blind/visually impaired persons); and deaf-blind individuals in the community.

Etiquette: Interpreters must be concerned with appropriate etiquette. Interpreters serve as cross-cultural communicators. When serving as a liaison between deaf and hearing cultures, it is important to understand not only the language, but the values of each group. Members of the deaf community who are losing their vision, or who have lost it already, may be going through a particularly difficult time. The deaf community places an especially high value on vision; the interpreter should be sensitive to this element in their total picture of interrelationships with consumers who are deaf-blind.

Another aspect of etiquette is social

greeting. How do you walk up to a new person to begin a conversation? A person with Usher syndrome will seem to be able to see you; you must remember that they have minimal or no peripheral vision. Therefore, if you approach them from the side and start to sign, they won't see you. You should approach slowly, giving them time to notice you coming and to find you within their visual field. When approaching totally blind people, touch their arm, then give them a chance to stop whatever they are doing. When beginning a conversation, start off with your name and communicate very slowly, giving both of you time to adjust to each other.

Conclusion: As you can see, interpreting with this community is diverse and challenging. It is important to know whether your listeners have any residual hearing or vision, their preferred language and communication mode, and the setting and logistics of the intended

communication interaction. Knowledge of these factors will greatly assist in creating a successful interpreting experience.

## **LEONIS ADOBE DELIGHTS DEAF-BLIND VISITORS**

by Kurt Pitzer

(Reprinted with permission of Los Angeles Times, Los Angeles, CA)

Hands flew fast and furious in silent conversation recently as 60 deaf and blind visitors from throughout the United States toured the Old West-era Leonis Adobe in Calabasas.

"It's so pretty," said Kathleen Spear of Pennsylvania, who is deaf and blind, as she rubbed a shoe worn by the wife of settler Miguel Leonis. "What color is it?" Outside the historic ranch house, some of the more than 40 volunteer specialists tapped the hands of their adult companions, translating letter by letter the



history of Leonis, who ruled most of the western San Fernando Valley with an iron fist during the late 1800's.

Other groups gathered at displays set up by the Adobe staff to feel tools and artifacts from the Wild West days.

"It's a spice grinder," Pat Scepan said, tapping the words into the hand of Lois Finocchiaro, who is both blind and partially deaf. Finocchiaro seemed not to understand until her hand found the object and she began turning the antique handle. Then her face lit up with recognition and she was eager to move on to the next object - an early waffle iron.

"We picked out some of our best objects to feel," said Phyllis Jones, director of the Leonis Adobe. "Other than that, this is alot like our regular tours."

The visit to Calabasas was part of the weeklong itinerary for about 350 delegates to the American Association of the Deaf and Blind's 17th annual convention. The

event, held in previous years in mostly eastern and southern cities, was hosted by Cal State Northridge this year.

The schedule for the blind and deaf and their interpreters, many of whom also traveled from the East Coast for the convention, included self-help and other workshops, games, dances and trips to Olvera Street, Venice Beach and various amusement parks and cultural centers.

"Without an interpreter, it would be very difficult to understand and communicate in places like this," motioned Stephen Erlich, a Seattle resident who says he was the first totally blind and deaf person to earn a master's degree from CSUN. "But a skilled interpreter really enables me to enjoy all of this."

## **DEAF-BLIND TOUR REAGAN LIBRARY**

by Terry Kanakri

(Reprinted with permission of Daily  
News, Simi Valley, CA)

Melvin Bell carefully touched an ivory model of the Statue of Liberty inside the Ronald Reagan Presidential Library on Tuesday.

Deaf and blind, Bell said that experiencing the statute and other gifts to the former president by feeling them with his hands was like touching history.

"They were very, very, very beautiful - wow," Bell said through an interpreter. "It was a unique experience to feel the objects. I think it's something that should be made accessible in all other museums."

Bell of Elizabeth, NJ, was one of about 100 members of the American Association of the Deaf-Blind (AADB) and support staff who received a special tour of the library in the southwestern Simi Valley overlooking



the Tierra Rejada Valley.

The group was part of a larger contingency that attended a national convention at California State University, Northridge, offering workshops on independent living, assertiveness and other educational programs.

The library visitors were given a special tour of the basement, where they were able to see or touch thousands of artifacts not on display. Then the group received a special tour of the museum exhibits.

For Thomas Peters, second vice-president of the AADB, standing next to a piece of the Berlin Wall outside the library was an emotional experience, he said through an interpreter.

"I'm impressed most of all with the Berlin Wall because it broke the barrier between East and West," said Peters, 44, of Hartford, Connecticut. "You can compare it to the struggle of the deaf and blind, you have to break the barrier. I want

to break down the wall, I want to improve accessibility."

For Ruth Catlin, 44, of Sun City, Arizona, who was born deaf and became blind at the age of 30 due to eye disease, feeling the historical artifacts was an experience she said she always would remember. "I really liked it," she said. "I felt like I was touching history. I was looking forward to it."

Rustie Rothstein, a member of the association's convention organizing committee who helped schedule the library visit, said the event helped to put a human face on the Reagan presidency.

"I think they'll get a new appreciation for who President Reagan was as a president," she said. "I think alot of disabled people tend to think of him as someone who cut disability-related programs. This will show them a different side of that, a more human side."

Daniel Saint James, an interpreter with

the group, said many deaf and blind members of the American Association for the Deaf-Blind will never have an opportunity to be so close to historical artifacts again.

## **USHER SYNDROME SUPPORT GROUP**

By Loretta S. Roults, Rehabilitation  
Counselor, HKNC, and Ilene D. Miner,  
Social Worker, HKNC

Although people come to Helen Keller National Center with many different kinds of vision and hearing problems, every so often there are groups of people who share similar backgrounds and life experiences. This was the situation in the fall of 1992 when, suddenly, there were six people, all with Usher syndrome I, all of whom had grown up in the deaf community and all of whom use American Sign Language as their primary mode of communication. During the intake and evaluation period



some interesting issues came up and we realized that these students were struggling with similar issues. The names of the students have been changed because they did not have the opportunity to discuss this article before it was written, and some have already left the Center. Following are some of the issues that the students raised.

Mary came from the midwest, a rural area, and she had never met another person with Usher syndrome. Barbara had a sister with Usher syndrome but the two sisters lived in different states and they could not get together to talk about vision loss, so Barbara felt herself to be alone. Jane's ex-husband has Usher syndrome, and so does her son. Although they share the same disease, Jane realizes that her needs and her son's needs are different. Bob isn't married, but he was a working person who lost his job when his eyesight began to deteriorate. He felt cut off from

his deaf friends who seemed to have little patience with him. Mary also complained about the impatience of people in her club for the deaf in the midwest.

Everyone expressed confusion to his or her rehabilitation counselor about how they had gotten this disease. Even though each one had some idea that it came from the family, there was confusion because no one in the family had the disease. They sometimes felt that their parents had ignored them, or not spent time with them, or had hidden the problem for a long time. Some of the students talked about feeling different and strange ever since their early years in residential schools because they were clumsy but didn't know why.

After noting the same issues being brought up repeatedly, Rehabilitation Counselor Loretta Roulton proposed the idea of an Usher Syndrome Support Group on a weekly basis. A primary difficulty in establishing this group was finding a

minimum of five good interpreters for the students involved. Some students used tactile methods of communication due to their limited vision and required one-on-one interpreting.

When the group began meeting, the students were extremely enthusiastic. They used American Sign Language for communication with Ms. Roult, the leader of the group who is herself deaf. Additionally, Social Worker Ilene Miner, who is hearing and fluent in sign language, was hired and asked to work with Ms. Roult and the group.

The group meets weekly with the agenda being decided by its members. Special guests, speakers and resources are made available on request. Members have described the group as being one of the most important parts of their experience at the Helen Keller National Center. The students feel that being able to share their mutual concerns with more than one



person at a time has been important in helping them to feel connected to others, to feel involved and to find out what others are thinking at the same time.

There has been a lot of discussion about family and spouse reactions to vision loss. Often the spouses of students are deaf but do not have a visual impairment. Members felt that their spouses often forgot about the visual problems they were having, and did not take that into consideration when communicating. Members felt anger at their loss of independence and family role and were thrilled about what they were learning at the Center. One student was excited about being able to manage in the kitchen again.

Some students expressed delight about the simple act of going into town for a haircut; about having mastered the mobility skills necessary to safely navigate in the neighborhood. All were excited thinking about the possibility of employment for the

first time without finding the barriers too overwhelming.

The group was also fortunate to have some wonderful guests. Henry Buzzard, well known in the deaf community of New York and formerly librarian of the New York State School for the Deaf in White Plains, visited the group and, with his marvelous wry sense of humor, related his experiences such as the hard time he had giving up driving and other adaptations in his life that he had had to make in dealing with Usher syndrome.

Another outstanding visitor was Dr. Sandra Davenport, a geneticist with a special interest in Usher syndrome. One of the issues she discussed was the genetic transmission of Usher syndrome. She explained that many of the materials and aids that genetic counselors use are printed charts. These charts are not useful to people who are blind and deaf. Dr. Davenport is a pioneer who has created

tactile materials for explaining the transmission of Usher. Using these materials and her extensive knowledge to demonstrate, the students found themselves holding cups of different sizes representing dominant and recessive genes. Baggies with pipe cleaners were used to represent cells and chromosomes and soon the members of the group began smiling and telling their family histories to each other and to Dr. Davenport. The feedback from the group to Dr. Davenport was excellent. Members said that for the first time they understood how the recessive gene could remain hidden in their families for generations and then surface again.

The plan is to continue the group meetings on a weekly basis as long as the members wish to continue while they are at the Helen Keller National Center. Ms. Roult gave a presentation on deaf culture and the group is starting to think about the issues that make them, as deaf-blind



people, both the same and different from people who are deaf-sighted, the first step in determining a deaf-blind culture.

Hopefully, when members return home, they may be able to establish similar Usher groups which will allow them to continue sharing their common issues and experiences. It can help them to increase their self-awareness and self-esteem.

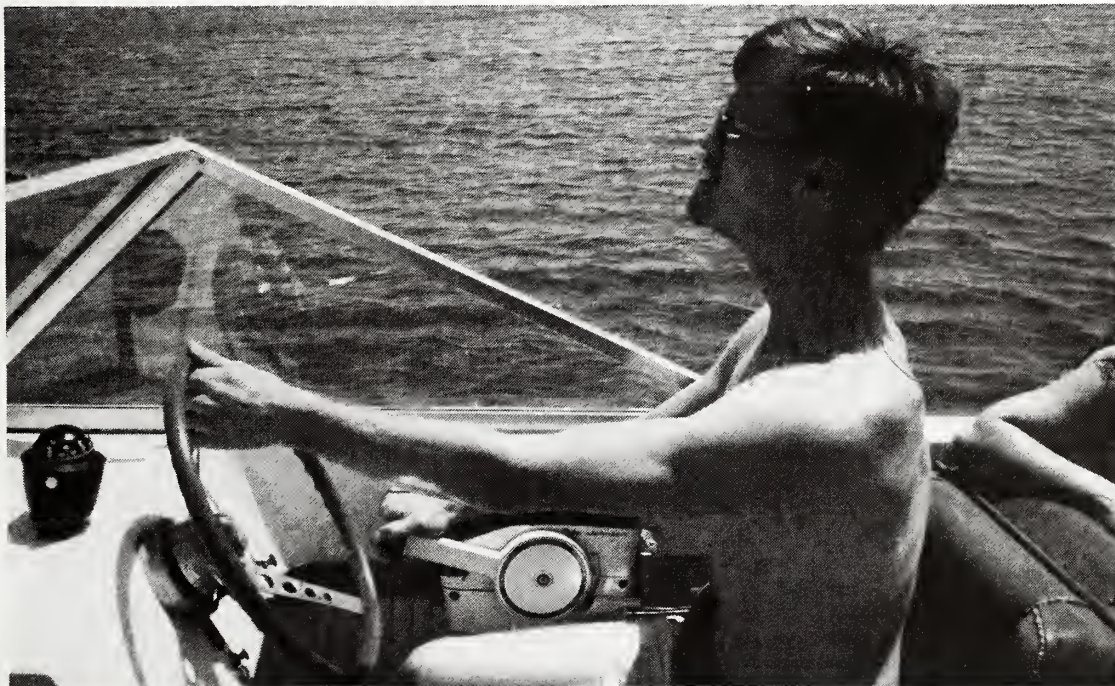
### **LIFE'S A BEACH!**

By Allison Burrows, Administrative  
Assistant, Community Education  
Department, HKNC

On a picture-perfect Saturday in July, students and staff braved the infamous Expressway and headed east to the summer community of Shelter Island nestled in between the two forks of Long Island. Arriving in Greenport, they boarded one of the many ferries which shuttle back and forth from the mainland, finally arriving

at a private home located on the beach in West Neck Harbor.

Without hesitation, the students headed for the sand and the crystal clear waters for a refreshing swim after their long journey. While some preferred to drift on rafts and rowboats and bask in the sun, others boarded a 19-foot motorboat. With Captain Andy "the old salt" Stender from Pennsylvania at the wheel and staff in crew, they sped off into the empty harbor, enjoying the wind and salt air.



Captain Andy in charge.

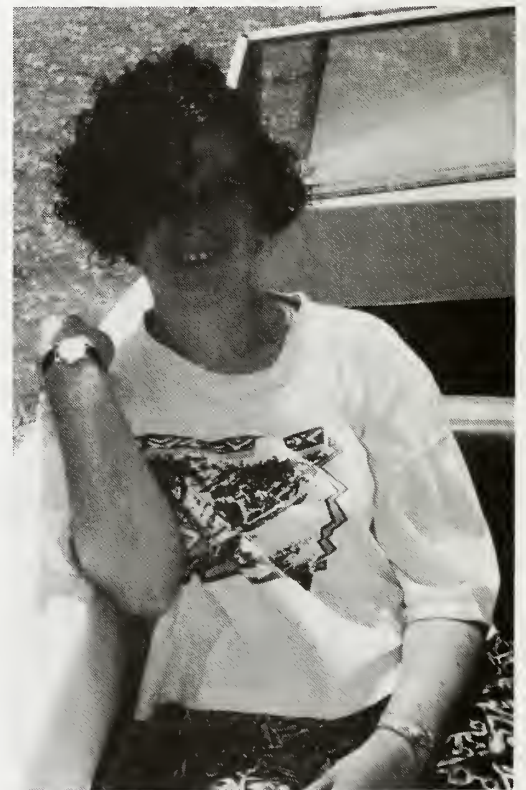




Captain Andy and Thordis Setbacken cruise the harbor.



Sheila Brines and her mother enjoy the boat.



Shannon Moteles soaks up the sun and enjoys the ride.



Beverly Kessner from Ohio decided that floating in a tube was not exciting enough and asked to be towed behind the powerboat. Not to be out done, Theona Chioccioli and Michelle Lloyd from Pennsylvania, Sheila Brines from Kansas, Shannon Moteles from New Jersey, Thordis Setbacken from Tennessee, Marcus Velasquez from Missouri and Andy Stender followed suit and bounced away in the wake, enjoying the spray and fresh air. Maggie King from Chicago played it safe and supervised the activities



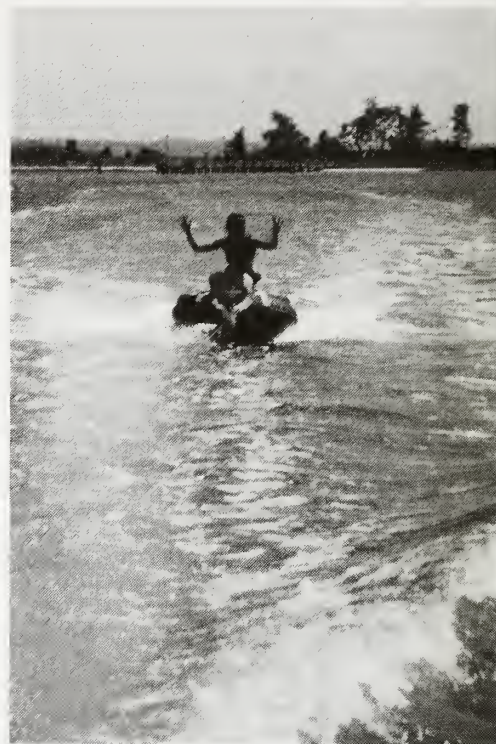
Beverly patiently waits for her ride to begin.



from the shore.



Theona and Clare Szigethy, recreational specialist, prepare for take-off.



Clare and Thordis under way.



Michelle, Marcus and Carol Ann Walsh, volunteer, go for a ride in the rowboat.



In spite of protests from Marcus, who was adrift in a rubber raft offshore, a "rescue at sea" was successfully executed by several students and staff in the speedboat.

It was an exhausted but cheerful, sun-drenched crew that piled back into the HKNC van for the return trip to Port Washington.



Marcus is towed to shore.



## **GETTING A FEELING OF REALLY HELPING**

By Rubaina Azhar

(Reprinted with permission of Newsday,  
NY)

To 18 year old Scott Codey of Port Washington, working with deaf and blind adults has been a special "high." Sitting on his parents' back porch, picture perfect with a white swing, freshly cut flowers and a generous dose of summer sunshine, Codey spoke enthusiastically of his experiences as a volunteer and an employee at the Helen Keller National Center (HKNC) in Sands Point, NY.

"There's something very special about being in a situation and feeling as though you've really helped," Codey said. "Working at the Center was the most valuable experience of my high school career."

Codey started volunteering at the Center shortly before he became a student at Paul D. Schreiber High School in Port Washington. At his graduation in June, he received an award for his community service. Throughout his time at Schreiber, Codey dedicated his Saturday evenings to volunteering at the Center. His exposure to and interest in the Center was a consequence of his uncle, Charles Codey, a graduate of the Living Innovation in a Functional Environment Program (LIFE) at HKNC. The LIFE program provides the Center's students with "support and the skills they need to function in a group home," Codey said.

At the Center, students have "alot more freedom than they do at an institution," he said. "It's a more relaxed atmosphere but still very structured." Among the chores LIFE students learn are preparing their own meals, mopping floors, washing dishes and shopping at a supermarket. Currently, the

Center has five such students. They vary in degrees of blindness and deafness and most are in their 20's or 30's.

As a volunteer, Codey's primary duty was to assist and befriend a young man from Missouri named Calvin Stallings. Stallings, who is 26, was born deaf and lost his sight at about the age of 14. "I became very attached to Calvin," Codey said. "I was able to communicate with him beyond telling him what to do. We could share jokes." The Center uses various modes of communication with its students including American Sign Language, signing into the palm and braille.

With his hands rapidly signing, Codey animatedly recalled his conversations and antics with Stallings. The two used to go swimming and shopping together and enjoyed trips to fast-food restaurants. Stallings completed his training in April and returned to his home state. "I felt so much a part of his accomplishments," Codey



said. "I'm very interested in what he does, where he goes. I plan on keeping in touch. I'll probably be making a visit out to Missouri."

Coordinating with the Human Relations Committee at Schreiber, Codey also arranged for about 30 other high school students to volunteer at the Center. "When kids listen to how fun it is, how easy it is to make a difference, they want to get involved," he said.

In February, Codey was hired by the Center as a part-time habilitation specialist. "I'm basically doing everything I was doing as a volunteer. Before, I was only working with Calvin - now I'm working with all the students."

Codey plans to attend Earlham College in Indiana this fall. He is considering special education as a major, among other possibilities. "I don't want to make the mistake of being too focused," he said. "I didn't go to the Center with some kind of

agenda. It wasn't a stepping-stone. Even if I don't go into this as a profession, I'll always have this experience."

## **HERE AND THERE**

Job Opportunities for the Blind (JOB) is a joint program of the U.S. Department of Labor and the National Federation of the Blind. It now offers three publications concerned with the Americans With Disabilities Act of 1993: TAKING THE MYSTERY OUT OF ADA; HOW TO HIRE A COMPETENT BLIND EMPLOYEE: REASONABLE ACCOMMODATIONS AND THE ADA; AND NEGOTIATION PRINCIPLES FOR REASONABLE ACCOMMODATION. The series, as a part or as a whole, is available free of charge by contacting: Lorraine Rovig, Director of Job Opportunities for the Blind, National Federation of the Blind, 1800 Johnson Street, Baltimore, MD 21230.

\* \* \* \* \*

BNA Plus, the Special Projects Division of the Bureau of National Affairs, announces that the AMERICANS WITH DISABILITIES ACT MANUAL newsletter is now available in braille. The six-to-eight page monthly publication provides prompt notification of the issues surrounding ADA's information and reinforcement, perspectives on ADA rules, plus court decisions and policy guidance from EEOC, the Justice Department, the Transportation Department, and the Federal Communications Department. Price for a one year subscription is \$150.00, plus applicable sales tax. For ordering or further information, contact: BNA Plus, 1231 25th Street, N.W., Washington, DC 20037, telephone (202) 452-4323.

\* \* \* \* \*



ABOUT US is a quarterly newsletter for persons with Usher syndrome II. The purpose of this newsletter is to serve as a forum for those who have the dual sensory disability of hearing loss and Retinitis Pigmentosa. Contact: Dorothy Stiefel, Editor, P.O. Box 8380, Corpus Christi, TX 78468-0388, hotline (512) 852-8515.

\* \* \* \* \*

The American Printing House for the Blind has produced an up-to-date atlas in braille that includes 38 maps and descriptions of such features as the Solar System, Earth's Seasons, and the International Dateline. This atlas is suitable for all ages. The price is \$19.95 and the order number is 2-06000-00. Contact: American Printing House for the Blind, 1839 Frankfort Avenue, Louisville, KY 40206.

\* \* \* \* \*

Rainbow Express invites requests for its catalogue. For a copy, send \$2.00 and specify if you wish to receive it in braille, large print, or on cassette. Among the items featured are: music items, jewelry, and some furniture. To order, contact: Rainbow Express, P.O. Box 92493, Nashville, TN 37209.

\* \* \* \* \*

Ruby Tuesday restaurants across the United States now offer menus in braille and large print, produced by the Tennessee School for the Blind. Ask for one of them when you next dine in one of the 150 Ruby Tuesday locations.

\* \* \* \* \*

Braille-Tac signs are designed to comply with ADA regulations. For a catalogue describing signs available, contact: Braille

Tac Advanced Stamp Works, Inc., 3271  
East York Avenue, St. Paul, MN 55101.

\* \* \* \* \*

The Northern Nevada Braille Transcribers group has available for loan several autobiographies of deaf-blind persons in Grade II braille. These include: ON DIFFERENT ROADS, by Geraldine Lawhorne; THE STORY OF ASLAUG, by Aslaug Haviland; OUT OF THE SHADOWS, by Don Petty and parents; IN HIM THERE IS NO DARKNESS, by Jean Ellzey; and THE MADNESS OF USHER's, by Dorothy Stiefel.

Braille readers wishing to borrow any one of these books should contact: Mrs. Lois Baskerville, Northern Nevada Braille Transcribers, 1015 Oxford Avenue, Sparks, NV 89431.

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**NAT-CENT NEWS**

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FOR DEAF-BLIND  
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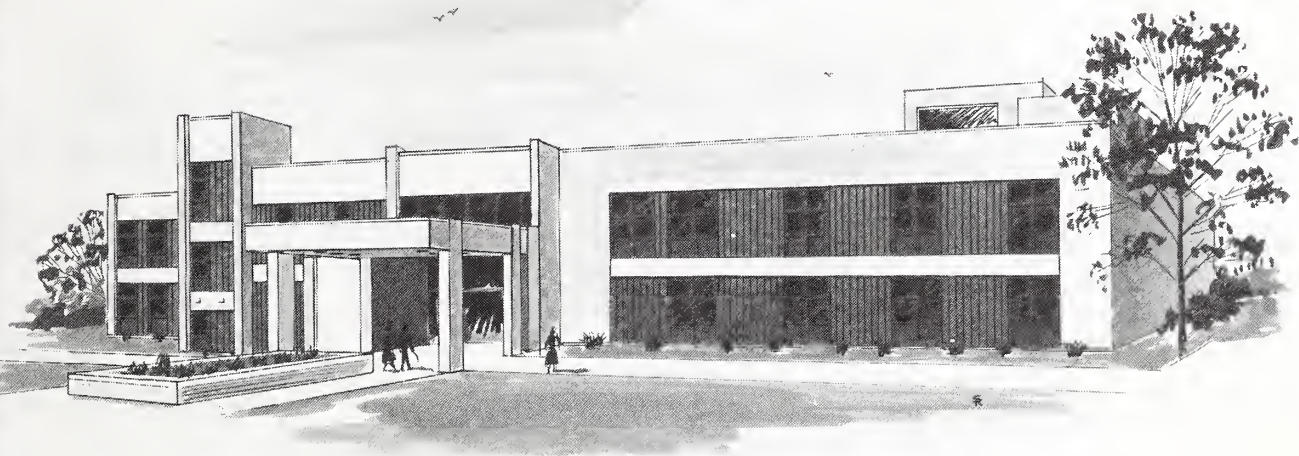
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## **EDITORIAL**

### **THE NOTE TELLER**

by Robert J. Smithdas, LHD, Litt.d., LHD

Several years ago, while browsing through a catalogue of aids and devices for people who are blind or visually impaired, I came across an item that intrigued me. It was a money identifier - a device into which one slipped a paper bill and a voice synthesizer would announce the denomination.

The money identifier, a small, portable device, seemed an ideal solution to the old problem of separating currency into its various denominations. Unfortunately, there were two obvious drawbacks for a deaf-blind user. At over \$600, it was too expensive and the audible announcements were useless to anyone who could not hear. Eventually the identifier was dropped from the catalogue (probably because of its high cost).

Then, just over a year ago, while

reading a computer magazine, I came across a similar device called the Note Teller being produced by a small company in Canada called Brytech - at a much lower price. The Note Teller also used synthetic speech to announce the denominations of bills, but it occurred to me that it could be changed so that it would produce vibrating signals that could be felt and distinguished by a person who is deaf-blind.

With this idea in mind, I called Mr. Earl Bryenton, president of Brytech, a division of E. L. Bryenton and Associates Inc., in Nepean, Ontario. I asked whether the Note Teller could be modified to produce vibrating signals similar to those used for Morse code. Mr. Bryenton was extremely interested and promised to consider my suggestion and explore its possibility. Two months later he sent me a Note Teller which had been modified to use a small separate vibrator.

I immediately began testing the Note Teller and I found that its vibrating signals

were easy to learn and tell apart. For a few weeks I kept the device at home, then decided to share it with others. I gave it to Jim Belanich, computer specialist at the Helen Keller National Center, to show the Center's students.

After testing it for a month, Jim reported that the students had no difficulty in learning to use the device and that they all liked it. He also stated that he believed it would be essential for any deaf-blind person who planned to live alone in an independent setting.

More recently, Mr. Bryenton sent me the new Enhanced Note Teller with the vibrator built into the device itself. This model has stronger vibrating signals that are easier to feel. It is also currently being tested with students at the Center. The Enhanced Note Teller is a small, compact device that operates on a 9-volt flat radio battery. Weighing only a few ounces, it fits easily into a pocket or a purse. Though still not inexpensive, its cost will



be less than that of the original money identifier and it is possible it could be subsidized by agencies serving the deaf-blind population. Brytech has indicated that, because such a device is difficult to evaluate for marketing, the Enhanced Note Teller may need to be produced on special order directly from the company.

Is the Enhanced Note Teller worthwhile? I have personally found the device very useful. It eliminates the need to ask sighted friends to help me sort out paper currency. And I agree with Jim Belanich that it could be an asset for a deaf-blind person living independently.

(For information concerning the Enhanced Note Teller, write to: Earl L. Bryenton, President, Brytech, Suite 102-28 Concourse Gate, Nepean, Ontario K2E 7T7 CANADA

## **FIELD NOTES**

by Dennis Brady, Assistant Director,  
Field Services, HKNC

We hope that the holidays were a good time for you. They can be busy and fun-filled but sometimes very stressful. For most of us it is the height of winter, so stay warm and in touch with friends. In fact, we'd like to hear from you. Let us know what is happening in your community; let us know what you'd like to hear about.

Last Fall, HKNC Field Services staff met in Seattle, Washington, for a staff meeting and a workshop on Usher syndrome. The workshop was arranged by HKNC's Technical Assistance Center.

People who are deaf-blind, family members and service providers had three days to meet one another, learn new things and talk about what needed improving. Most of us had the opportunity to enjoy some great food at Delcambre's

Rajin Cajun Restaurant. (Many of you will remember the NAT-CENT NEWS story from September 1992 about Danny and Holly Delcambre). The restaurant is doing well. One evening we filled every table and had our own version of a Mardi Gras celebration!

Field staff members (l to r) Suzanne Earle, Pat Rachal, Barbara Martin and Kathy McNulty discuss the issues.



The Rajin Cajun Restaurant is the choice of field staff members (l to r) Monika McJannett, Pat Rachal, Joan Houghton, Kathy McNulty, deVergne Goodall, Rod Ferrell and JoAnn Enos.



One of the issues that came up during the workshop was the use of Vitamin A and Vitamin E for those with retinitis pigmentosa. The RP Foundation has an excellent article on this subject. You really must speak with an ophthalmologist about these vitamins before deciding what to do. Research does show some benefits from Vitamin A for those with RP. The research also shows that large amounts of Vitamin E can be harmful. This is a very complicated issue. That's why it is important to talk with your doctor about it. Call the RP Foundation Fighting Blindness in Baltimore for information. Their phone numbers are TTY 1-800-683-5551 and Voice 1-800-683-5555.

I am not sure how many of you know of a national organization called ADARA. It is the American Deafness and Rehabilitation Association. They work on behalf of deaf people throughout the United States. They have 15 local chapters and 6 special interest sections. One of the special

interest sections is deaf-blindness. I am currently the chairperson for this section. I need you to tell me what are the concerns you want raised with ADARA.

Although most of the members of ADARA are part of the Deaf Community or are culturally deaf, ADARA can get involved in any issue of concern to people who are deaf-blind. ADARA publishes a newsletter four times a year. I will be submitting items related to deaf-blindness so please send me your ideas, your stories and your concerns. Organizations like AADB, ADARA and NAD (National Association of the Deaf) have worked together recently and have been successful. An excellent example of this team effort was getting the Americans with Disabilities Act passed by Congress and signed by the President. Let me know what you want ADARA to focus on in the future.

## **DEFINITION OF DEAF-BLINDNESS**

In the past year, deaf-blindness, previously considered a dual disability, was designated a single disability because of the unique problems it presents for an individual who has hearing and visual losses in combination. The following definition of deaf-blindness which was subsequently adopted, though technical in context, may be of interest to many readers of NAT-CENT NEWS.

\* \* \* \* \*

The term "individual who is deaf-blind" means any individual:

(A) (i) who has a central visual acuity of 20/200 or less in the better eye with corrective lenses, or, if there is a field defect, central acuity of 20/200 such that the peripheral diameter of visual field subtends an angular distance no greater than 20 degrees, or a progressive visual loss having a prognosis leading to one or both these conditions;



(ii) who has a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, or a progressive hearing loss having a prognosis leading to this condition; and

(iii) for whom the combination of impairments described in clauses (i) and (ii) cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation;

(B) who despite the inability to be measured accurately for hearing and vision loss due to cognitive or behavioral restraints, or both, can be determined through functional and performance assessment to have severe hearing and visual disabilities that cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining vocational objectives; or

(C) meets such other requirements as

the Secretary of Education may prescribe by regulation.

**THIS GARDEN'S DELIGHTS:  
TOUCH AND SMELL**

by Betty Ommerman

Reprinted with permission from  
Newsday, NY

Ask most people what they think of a garden and they'll tell you how beautiful, or interesting it looks. Communicate that same question to someone who is blind and he or she will comment on the touch and smell of the various plants.

And, according to Barbara Hausman of the Helen Keller National Center in Sands Point, it's the touch and smell that's stressed at this Center. Known as the Sensory Garden, it is celebrating its 10th anniversary this year.

The garden was part of the Center's first "Fall House and Garden Tour," which included a visit to four Sands Point homes

and gardens and tea at the Sensory Garden.

The Sensory Garden, also known as the Fragrance Garden, was the suggestion of Sands Point Garden Club member, Alvina Wiles.



**The Fragrance Garden is a popular spot with students. Shown above are recent students (l to r) Linda Carter, Tina Dowdy and Bradley Cupit.**

**Photo by Geraldine Espana**



"To build the garden, we chose Herbert Cohen, then chairman of horticulture at the State University at Farmingdale, as our designer and architect," Helen Bachko of the Sands Point Garden Club said.

Connected guideposts lead visitors safely along walkways and patios that vary from brick to scored concrete to bluestone. Raised redwood planters grow various herbs noted for their fragrance. These include lemon balm, oregano, rosemary and spearmint. Textured plants that appeal to the touch include the wooly lamb's ears, junipers, dwarf boxwood, Japanese holly and yews. Benches in the shade of a honey locust allow visitors to rest and enjoy the fragrances.

## **PATH PROGRAM**

by Mary Korpi, Supervisor, PATH  
Program, HKNC

A new program has begun at HKNC. It is called the PATH Program (Person-

centered Approach to Training and Habilitation).

The PATH program is designed to facilitate independence training and skill acquisition for students who benefit most from a functional approach to training. The program focuses on providing personal adjustment training in communication skills, orientation and mobility, daily living skills, and socialization skills that will enhance an individual's employability.

The program is designed to maximize training opportunities by providing a small group setting in which clear expectations for training are established. The PATH student is motivated throughout the day to utilize their individualized communication methods by a core group of staff who work consistently with this same student. The PATH Program is designed to provide training at naturally occurring times and in functional settings. For example, a student is asked to brush his or her teeth during the morning grooming routine.

Staff maximize this opportunity for communication and utilize a wide variety of methods for fostering communication with the student. Communication methods may include: signing, pictorial symbols, object cues and gestures.

Each PATH student begins his or her program day with assistance from staff to wake up and begin his/her grooming routine. The focus of this training is to develop appropriate supports for the individual which will enhance their independence in this area. Upon completion of morning grooming, students either go to breakfast in the cafeteria and participate in the family-style dining program or make their own breakfast in the group home breakfast program. Breakfast is followed by communications class. This serves as an orientation to daily events, enabling the student to participate, make choices, and initiate daily activities. The staff develop and review individualized schedules for each student.



The communication class also serves as a reference point for greeting peers and socializing before beginning work.

PATH students participate in approximately three to four hours a day of various work-related activities. Work training may occur in the on-campus workshop style setting or in various settings both on and off campus. Students have the opportunity to explore a variety of jobs, including: janitorial, food service, clerical, laundry, recycling and/or anything which may be motivating to an individual. Through these meaningful work activities and other training activities, the goal is to assess students' interests, abilities, training and support needs. An additional information-gathering tool is the development of a Personal Profile gleaned from mapping done in the Personal Futures Planning. This mapping process generates helpful information which can be integrated into programming, specifically vocational programming. An individual's

preferences, dislikes and communication skills are considered to develop a good job match.

Vocational training before and after lunch break is followed by participation in Socialization Group. Emphasis here is placed on increasing peer interactions developing skills and interests to make constructive use of leisure time.

Plans are being made to continue the PATH program into the evening hours to further enhance leisure time opportunities and to facilitate a smooth carry-over of goal-based training particularly as related to communication, socialization, and personal management.

Your comments and feedback are welcomed concerning this exciting new program.

# **AN OPEN LETTER TO THE DEAF COMMUNITY: We Have Usher Syndrome**

This article was written by the following students, both past and present, at the Helen Keller National Center: Theona Chioccioli, Pennsylvania; Syble Harrison, Oklahoma; Beverly Kesner, Ohio; Janice Lejeune, Louisiana; Andrew Stender, Pennsylvania; Winifred Tunison, New Jersey; Rosenda Herrada-Benites, Maryland; Frank Levine, Georgia; Joey Lugo, Pennsylvania



Several of the authors, (top row, l to r) Frank Levine, Andrew Stender, Joey Lugo, (bottom row, l to r) Winifred Tunison, Theona Chioccioli and Rosenda Herrada-Benites gather for their meeting.



We are deaf people with Usher syndrome, Type I, who grew up in the Deaf Community and who now have significant visual loss. We don't spend enough time with our old deaf friends any more, although we wish we could. We decided to tell you about our Usher syndrome and how it has affected us. We also would like to give you some tips for communicating with us and make a few requests that will make our lives easier.

There were originally six of us who met weekly here at Helen Keller National Center for several months to talk about issues related to our Usher syndrome; some of us have already returned to our home states and new people have joined us. This article comes out of our meetings together.

Although we came from different parts of the country, we didn't know each other before arriving here. We also come from different backgrounds, but we have become good friends brought together by our need to learn new skills.

What is Usher syndrome?

Usher syndrome is a genetic condition comprised of congenital deafness and retinitis pigmentosa. For us to have Usher syndrome, both of our parents must have had the recessive gene for it. If only one parent had the gene, we would not have the syndrome although we might have been carriers. Usually the retinitis pigmentosa is not diagnosed until adolescence or later.

We have a problem with the retina, the part of the eye that captures the light. The cells start to die and our eyes don't work well anymore. Each of us is different. We have different vision, and different rates of loss. We started noticing problems at different ages. There are however certain common aspects to what happened to us.

How we experience our eye problem:

First we started to lose peripheral vision which means not only that we can't see to the sides, but also that we cannot see up

and down. It also means we have a smaller and smaller window to see things through. Some of us will lose our vision completely, and some of us won't, but there is no way to know who will and who won't lose all their vision. Of the nine authors, five of us have no usable vision and communicate tactually and the remaining four have enough vision to still communicate visually but need to sit far away from the people we are communicating with to see as much as possible through our "windows."

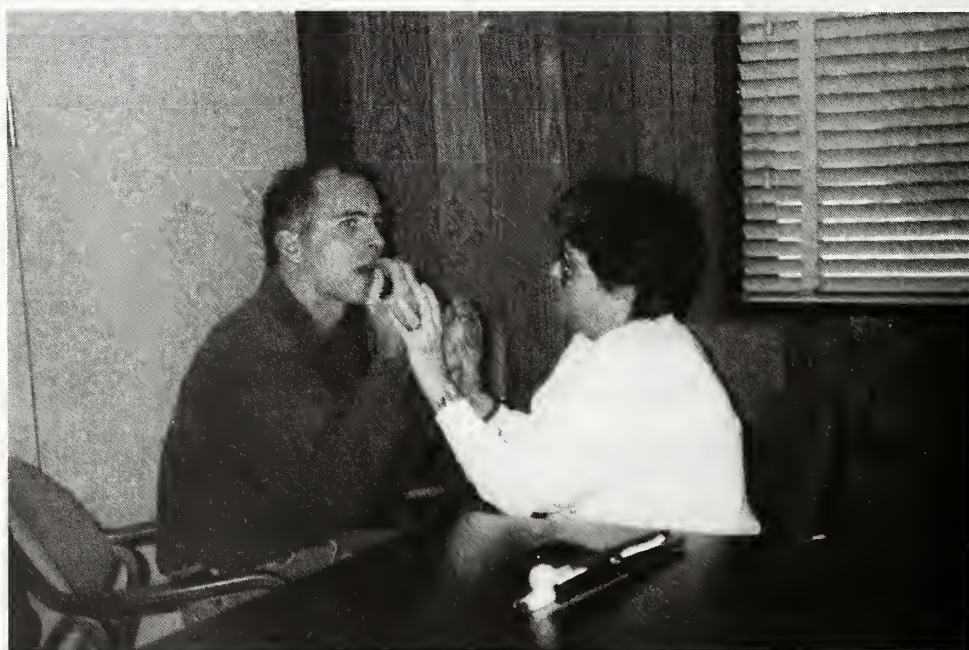
Another early sign of retinitis pigmentosa is problems seeing at night or in a darkened room. How much we see depends on the available light; sometimes we see more than at other times. Sometimes we look like we are getting around fine, and later in the evening we might need a cane or even a sighted guide. We may be fine and then suddenly reach for a friend's arm when we enter into a dark building. We might be walking outside and then go into a restaurant and ask you



to have the menu signed to us because we cannot see the print. We might be signing with you visually and later inside or at night, we might reach for your hand to communicate tactually.



**Winnie Tunison and  
Ilene Miner, interpreter**



**Joe DiRenzo, interpreter  
and Theona Chioccioli**

## Our meetings:

We have met weekly since February 1992, using interpreters, both deaf and hearing, to meet as a group. During our meetings we discussed our eyes, the genetics of this syndrome, how we found out we had it, guide dogs, programs around the country, other useful information, our relationships with old friends, family members, spouses, children, and community groups and how our lives have changed. We also have guest speakers. We have shared funny stories and sad stories. We wish to tell you some of it.

## Our feelings and experiences:

We, as deaf people, have always treasured our eyes, as we are sure each of you does. If, while you read this article, you can imagine suddenly not being able to read it, or anything at all, or think about not being able to leave your home without planning and possibly getting help, you



may begin to understand how we feel with Usher syndrome. The visual loss started slowly, and we had to adjust bit by bit. Ultimately the loss impacted on our lives and we had to change the way we live.

Remember that we are exactly the same people we were before we lost our vision with families, spouses, children, grandchildren, jobs, activities, hobbies, friends. Our vision loss impacts on everything. We would like you to understand us better because we have had some bad experiences with you, the Deaf Community.

We notice some of you have no patience with us; when you see a deaf-blind person, you turn away, or try to avoid contact with us. Some of us have been insulted by people who thought that they were teasing us. One member was told that her vision was worse than a horse with blinders on; the person who said that thought it was funny. It was painfully far from being funny.



One of our group mentioned going to the local club, reaching out to communicate with someone and having that person pull her hand sharply away, as if she could catch blindness. We have learned that many deaf people don't like to use tactual sign language; they pull away from us which is insensitive and insulting.

Some of us have sat in our deaf club with almost no contact from other club members and our friends for hours. We spend a lot of time alone, and when we come to the club, we are really hungry for contact, discussion, news, chatting and information. We also have ideas and opinions we want to share with you! We don't want deaf people to pull away from us - rejecting us because of our blindness.

Our thoughts and suggestions:

We would like to explain our communication needs and offer some ideas to help us understand each other better. First, we have to stand some distance

from the person we are communicating with so that we can see more of the person's hands, face, and body. Sometimes we ask you to sign small so that in our tunnel vision we don't lose sight of your hands. Sometimes we have to ask you again and again to stand back, and you think we are making up this problem and you don't want to be bothered.



Andrew Stender, Rosenda Benites and Joey Lugo with interpreters, M.J. Shahan and Suzanne Dooley.

Sometimes you forget to keep your signs small and start signing big again. We are embarrassed to remind you so we just

give up and smile and nod as if we understand.

We look like we are clumsy when we trip over things, or spill things we do not see. Some people think we are stuck-up and unfriendly because we don't see them and cannot respond to their waving at us from the sides. Some of our friends think we can see them coming toward us and they grab us to give us a hug and frighten us to death because we have seen nothing before being grabbed! Please touch us softly at first so we are aware that you are there.

When we are sitting with people at a table and someone puts a drink on the table next to us, we need to be informed. We probably won't have seen it there and the next time we move, we may knock the drink over.

Please tell us about things in our periphery that you think we haven't seen. We won't be insulted, and you will save us from a moment of embarrassment or



possibly from an injury.

For those of us who communicate tactually, the first thing we need to know is who is communicating with us! Identify yourself when you first touch us. It's strange to have someone touching our bodies and hands when we don't know who it is. Some people like to play a game of "guess who?". If it is a close friend, that is sometimes all right, but for others it is not an all right game; it makes us feel uncomfortable and embarrassed.

When you approach us, please sign naturally! If you are generally animated, then continue to sign that way. If you usually fingerspell a lot, continue to do it. Many people think they have to sign slowly, simply, and blandly for us to understand. But your sign is part of your personality! We want you to keep that because it is part of you - it is the way that we recognize you.

If you approach us and we are sitting and you are standing, please either sit

down with us or ask us to stand up with you. It is important for us to be at the same height for two reasons: it helps in understanding by helping us to mentally place your hands in space and it prevents both of us from getting muscle and arm strain from reaching up or down to communicate.

We also like our friends and our family members to let us know when they enter and leave the house. It is frightening to bump into someone we did not know was there, and it's a waste of time to be looking for someone who has already left.

We know that it may be time consuming to spend time with us because we can only chat slowly and with one person at a time. You are used to talking fast with many people at once. We ask you to be patient with us. You were our friends; don't ignore us or be afraid to communicate with us tactually.

It helps if you give us feedback while we are chatting by putting your hand

under ours - obviously we can't see you nodding your head! If someone else approaches us, you can let us know that someone else is there. If you need to watch them for a minute, let us know. It's polite to sign what the other person is signing to you; after all, if we could see, we would know what they were talking about. Most importantly, if you need to walk away, tell us. There is nothing worse than standing and chatting, thinking that we are chatting together, but then we reach out and find that you have left and we are signing to ourselves.

At home we also remind our families to tell us if they have invited friends over in order that we aren't surprised by bumping into someone we didn't know was there. Sometimes a family member moves a piece of furniture and forgets to put it back where it belongs or leaves a kitchen cabinet door open creating a hazard for us that causes us to smash our heads.

One of the difficult things about our



vision loss is losing independence. We don't like to ask for help but sometimes we must ask for a ride to the store or church, or for the favor of picking up something at the store. We hate to ask. We only wish that occasionally our friends would call to see if we need anything. We won't abuse by asking for help too often. If we do, please tell us. We will pay for any gas you use in driving us someplace.

It is tough to give up the independence we had - driving, shopping, visiting, doing things on the spur of the moment. No one likes to be dependent on others so often. We strive to be as independent as possible.

Our vision loss impacts on our families. They have had to adjust too. For some of us, our time with our families is different now. We miss some of our old hobbies. We miss not getting the news every day. Some of us insist that family members give us the news of the world every day so we can stay up-to-date.

We want you to ask us questions. If you aren't sure of how to approach us or communicate with us, let us know. We are happy to answer questions and we will let you know if we need changes in the communication for better understanding. We want to tell you about our families, jobs, and activities and we want to know about yours. We want to be involved in the life of our community, with the people with whom we have spent our lives. We don't want to be ignored, insulted, left out and hurt. We were your friends. Don't be afraid of us. Don't pity us. If you cared about us before, remember we are the same people we were.

We are each an individual with varied needs, but we find ourselves limited more and more to interacting only with other deaf-blind people. With each other we find comfort in sharing communication and other issues. We don't always have to explain our needs to each other, but we want more. We want contact with deaf

people who still have vision.

We grew up with you in our deaf world. We miss you. Please take a few minutes to be with us, don't be afraid . We don't like being isolated from the life of the community.

## **THE DEAF- BLIND SPEAKING GROUP**

By Kathie Anderson

In 1992, the Deaf-Blind Speaking Group (DBSG) was established at the American Association of the Deaf-Blind's (AADB) annual convention in Minnesota. This was an exciting event because members of this group, who share hearing-visual impairments, grew up in an oral tradition and were used to communicating with ordinary language, grammar and speech. They often felt "alone in a crowd." The group makes them feel welcome and comfortable with their peers.

Some of the members of the DBSG have lost all of their hearing while others



are hard-of-hearing. They feel a need to be able to identify with each other and to have a setting where their various and complex communication needs are not only met, but fully understood. With the help of the convention's Support Service Providers (SSP's), they receive communication by tactile sign language, limited space signing, fingerspelling, lip-reading, or by using assistive listening devices such as the FM system, hearing-aids and loop systems. Basically, however, each individual receives communication as accepted and provided.

In June 1993, the AADB convention was held at Northridge, CA, and the DBSG group met for the second time. Eleven new members, who are deaf-blind and oriented to oral communication, joined the group.

The DBSG is a subgroup, not a separate group, from the AADB nor is it a political or support group. When the group meets during the week of the AADB convention,

members can socialize and find support from each other.

In 1994, the AADB convention will be held in Greensboro, North Carolina. We hope to have the DBSG gatherings at the convention. If you are interested and want more information, please write to: Deaf-Blind Speaking Group, c/o Kathie Anderson, 4918-42nd Avenue South, Minneapolis, MN 55417. Or call: (612) 729-4630 (voice/TTY).

## **DUAL DISABILITIES HAVEN'T STOPPED THIS BUSINESS MAN**

Reprinted with permission from SIGHTS  
& SOUNDS, Alabama Institute for Deaf  
and Blind, Talladega, AL

The well-dressed, poised and confident business man entering the room on his wife's arm, exudes a warm and peaceful countenance that draws people to him.

Jerry Henderson is an achiever - a

success story. He operates his own vending business at Ft. Rucker near Dothan in Alabama. He's a Sunday School teacher, an avid reader, a devoted husband and he enjoys walking, jogging and riding an exercise bike.

He was also the first deaf-blind man in the United States to pass his GED and receive a high school diploma.



Jerry and Linda Henderson

Jerry was born deaf with Usher syndrome and attended the Alabama School for the Deaf. He left school to work at New Hope Industries in Dothan, and it was there that he met his wife-to-be, Linda, who worked as a receptionist.

Visually impaired herself, Linda left her job to train as a medical assistant. During the months when she lived in Atlanta, Linda and Jerry corresponded by mail. When she graduated, they were married and he taught her to communicate through



sign language.

Four years later, Jerry began losing his eyesight and eventually became totally blind. But he refused to give in to a world of silence and darkness and decided to pursue training in computers.

In 1980, he enrolled at E. H. Gentry Technical Facility, brushed up on the academics he needed - including math and algebra - and then passed the GED test to receive his high school diploma.

Jerry and Linda then moved to California where he enrolled in a computer training program. Halfway through the course, the federal government cut funding and the program folded.

The couple returned home to Alabama; Jerry enrolled in the Business Enterprise training program at E. H. Gentry and later obtained his own vending site in the headquarters building at Ft. Rucker. His business has now expanded to include 4 buildings. He does his own record keeping and paperwork, cleans and stocks the

machines, makes minor repairs and fills out orders for purchasing.

Jerry writes out his order on raised line paper. If a salesman has a question he can type his message on a Teletouch machine. Jerry reads the message in braille, then writes an answer on the raised line paper.

Jerry uses a braille adapter for his TDD (telecommunication device for the deaf), and a silent vibrating pager worn on the wrist signals him for phone calls, etc.

"He's very independent," says Linda. Jerry does a lot of the housework - including the dishes, the laundry and taking out the garbage. And he never wakes up late in the mornings, according to Linda. "He has a great body clock; he's always on time for work or church."

"Sometimes people stare or talk about us in public," Linda said. "We communicate through sign language so I guess they think I'm deaf too."

But this is "just natural life" for this happily married couple of 21 years.

"We've gone bowling, fishing and played miniature golf. Jerry even got a hole-in-one once," said Linda. "The kids in our family and in our church all love Jerry, as do most people when they get to know him," Linda said.

During the interview, Jerry patiently communicated by signing into his wife's hands. When conversation lingered with Linda, he sat contentedly.

A final question has to be asked - "Do you ever feel isolated, frustrated or maybe lonely when conversation goes on around you?" He smiled, and explained how he had accepted his "inconvenience."

"I just sit and wait," he said. "I can't see or hear people talk. But God is always near. We can love Him and fellowship with Him. When I need tenderness, I pray, and He gives me peace."



## **DEAF-BLIND GIRL TRIUMPHS AT HER BAT MITZVAH**

By Peter Baniak

Reprinted with permission from the  
Chicago Tribune, Chicago, IL

Nearly hidden behind a wooden podium at the front of the synagogue, a small girl in a flowered dress uses her nimble fingers to reach out to the world. She runs her fingertips over a braille translation of a passage from the Jewish holy book, the Torah. She then places her fingers in the hands of the rabbi and "listens" as he talks to her in sign language.

Then she turns and uses her fingers to tell a story from the Torah, a passage about a mother bird and her eggs, about respecting nature and animals.

It is 12-year old Maya Eldar's bat mitzvah ceremony, an event that marks the passage into adulthood for Jewish girls when they reach the age of 12. The bat mitzvah is an important event for all

women in the Jewish faith, but for Maya, the August ceremony in Skokie, IL, marked an exceptional achievement. Maya has been deaf and blind since birth.

"Today is a special day for Maya," the girl signed about her bat mitzvah. "It is a very good day."

Douglas Goldhamer, the rabbi at Maya's synagogue, Congregation Bene Shalomin Skokie, says he doesn't know of any other deaf and blind Jewish girl who has had a bat mitzvah. "This is a big milestone for Maya," said Faye Eldar, Maya's mother. "But she's already had a lot of milestones in her life."

Born 14 weeks premature, Maya weighed only 1 pound 9 ounces and was not expected to survive. When doctors discovered that Maya was blind and later learned that she also was deaf and suffered from a mild case of cerebral palsy, they held out little hope that she would live much of a life.

At age 3, Maya, an only child, was

labeled "too low functioning" to be admitted to a special school for children with disabilities.

Today, however, she attends Middleton Elementary School, a public school in Skokie. She rides a bike with the help of a guide, swims, rides horses, goes to overnight camp with her Girl Scout troop and hopes one day to become a veterinarian.

Maya's precociousness has led many to compare her with Helen Keller, the deaf and blind author and lecturer whose life and education have been the subject of movies and books. Keller lost her sight and hearing at age 19 months due to illness.

But Maya's parents avoid comparisons with Keller. "Helen Keller was not deaf-blind from birth - she knew how the world looks," says Arthur Eldar, Maya's father. "But Maya's concept of the world is that everyone else is deaf, everyone is blind. She's never known anything else."



## A PARENT'S VIEWPOINT

Reprinted from the Perkins School for the  
Blind Annual Report '92

Joyce Ford's younger child, Riley, was born three months premature, weighing only 1 pound, 13 ounces. He was 12 1/2 inches long and his legs were the size of her ring finger. "But," she says, "I saw him as perfect."

When Riley was 3 months old, she learned that her son was blind. At 10 months, he was diagnosed with cerebral palsy and glaucoma. At age 2, he was diagnosed as being severely to profoundly deaf. She and her husband were told to "look for a place where kids like Riley go, and get on with your lives."

Now, at age 8, she



Joyce and Riley

says, "Riley walks and runs. He roller-skates, swims, climbs, swings and jumps. He plays and laughs and hugs and kisses." And he's in the third grade. Joyce attributes his success to the partnerships she formed; to the support she and her family received for Riley.

And the strength of partnerships like these is increasing, thanks to parents like Joyce Ford and the Hilton/Perkins National Program. Two years ago, the Hilton/Perkins National Program became, she says, "a very, very strong partner" with the Helen Keller National Center in the introduction of the National Parent Network for the parents of multi-handicapped blind and deaf-blind infants and children. Beginning with 11 members two years ago and growing to more than 1,000 today, the network helps these parents find services and learn to advocate for their children. Joyce is currently serving a two-year term as chairperson of the national organization.

"The national approach gives parents a sense of direction so they won't feel alone," she says, a feeling she and her family so often felt in their quest for Riley's services. "The National Parent Network would not be what it is without the Hilton/Perkins Program."

"Hilton and Perkins set an example of partnership and support. We need both," she says, "and we need their energy to continue to move forward. The focus is on the kids and bringing good things to the kids. It's believing in possibilities, that things can happen if you persist in your beliefs - in what your heart tells you is right and good."

## **HERE AND THERE**

The National Braille Press, Inc., 88 St. Stephen Street, Boston, MA 02115 (Tel.: 617-266-6160), has available an updated listing of braille transcription services including prices and anticipated turn-



around time. Copies in braille are free of charge; a print copy is \$7,00.

\* \* \* \* \*

The 1993 AMERICANS WITH DISABILITIES RESOURCE CATALOGUE is a glossy, 13-page print brochure listing products and promotional services covering all aspects of the ADA, including: educational, hospitalization, housing, legislation, employment and transportation. Copies of this newly revised catalogue are available upon request from: Administrative Services Department, National Easter Seal Society, 70 East Lake Street, Chicago, IL 60601.

\* \* \* \* \*

The Diabetic Food Emporium, Ltd., of Hackensack, New Jersey, offers a list (print) of more than 400 sugar-free snacks, cakes, preserves, and other food which

may be difficult for diabetics to find in local stores. Orders over \$30.00 are sent without handling charges. For more information about the impressive variety of products, call toll-free: (800) 285-3210.

\* \* \* \* \*

Whirlpool Appliances Corporation has many overlays, special knobs, books and tapes which are designed to be used by people who are physically or visually disabled. Many of its publications are in braille, large-print, or on cassette tapes. Two booklets, DESIGNS FOR INDEPENDENT LIVING, and TOOLS FOR INDEPENDENT LIVING, suggest ways to modify kitchen and laundry facilities for more efficient use of appliances.

For information, call: Whirlpool Corp., Appliance Information Service, Consumer Assistance Center in Benton Harbor, MI, at (800) 253-1301.

Ambu-Tech's Identification Cane was designed for persons who have partial vision, but who may need a cane in difficult situations, such as crossing busy intersections or boarding buses. The ID Cane is 30 percent lighter than the standard mobility cane, and when folded, fits easily in a purse or pocket. The all-white cane is available in 35 to 54-inch lengths for \$14.00, or for \$14.75 if red reflective tape is added.

For information or to order, contact: Ambu-Tech, 670 Golspie Street, Winnipeg, Manitoba, Canada R2K 2V1; or call 1-800-561-3340.

\* \* \* \* \*

The Kahn Cane is designed to be kept in contact with the ground at all times. The side-to-side motion of the tip, as it moves across walking surfaces, gives constant information through the cane itself, as well as by sound given off by the



tip. It slides easily over most cracks and bumps.

For further details, contact: Kahn Cane Company, P.O. Box 524, Alameda, CA 94501; or call: (510) 521-3286.

\* \* \* \* \*

Greyhound's "Travel Assistance Policy" permits a disabled person to travel with a companion who assists when boarding or alighting from a bus. The assistant travels on the same ticket with no additional charge. If a disabled traveler wishes to travel alone, or keeps a battery box for a wheelchair, he/she can call Greyhound at least 48 hours prior to the time of departure, to advise Greyhound of his/her itinerary and any special circumstances relating to the disability so that proper assistance can be arranged along the route. Greyhound's "Telephone Information Center" takes these calls at: (800) 752-4841.

The Ann Morris Enterprises 1994 catalogue is now available. It lists over 150 items, many of them new. It has a wide range of products useful to blind persons for labeling, kitchen work and other areas of independent living.

Two items which may be of special interest to readers are a light probe and a vibrating mobility aid. Although the light probe is audible, it can be altered to vibrate; its signals grow in intensity as it is held closer to a light source. The vibrating mobility aid might prove useful in walking through a room; it scans an area 4-feet wide and six-feet high, making it possible to avoid walls, furniture and other obstacles in the area.

The catalogue on audible cassette, IBM disk, and in large-print is free; the braille copy is \$10.00.

For information or to order contact: Ann Morris Enterprises, Inc., 890 Fams Court, East Meadow, New York 11554; or call: (516) 292-9232.

## **WOMEN WHO MAKE A DIFFERENCE**

By Barbara Gerbasi

Reprinted with permission from FAMILY  
CIRCLE

For 54-year-old Linda Stillman, that November day in 1987 started out no differently from any other. The to-do list she made while gulping down coffee in her Great Neck, New York, home was filled with the usual errands, volunteer work and phone calls. However, during a routine eye exam that afternoon, her optometrist insisted she see a specialist immediately. A CAT scan revealed a tumor growing right through her optic nerve.

"I guess there were warning signs," Linda recalls. "Images weren't sharp, and sometimes letters appeared to jump off the page when I read. But I never suspected a serious problem. When they told me, I was petrified. My mother died of cancer when she was in her early 50's."

When the doctor said surgery to



remove the tumor might leave her blind, Linda's first thoughts were of Michelle Smithdas. How could they finish what they had started? Ironically, for the last three and a half years, Linda's eyes and ears had been functioning for those of Michelle, a 36-year-old deaf-blind woman who lived in nearby Port Washington. "Michelle was depending on me to help her get her master's degree," Linda explains. "I couldn't let her down."

Michelle was enrolled in the master's program at Columbia University's Teachers College in New York City, probably the first deaf-blind person to try for an advanced degree in an Ivy League school. "I knew I could do it if I had someone to help me," explains Michelle, who speaks haltingly and often communicates through an interpreter.

In a contemporary version of what teacher Anne Sullivan did for deaf-blind Helen Keller a century ago, Linda had volunteered to become Michelle's "miracle

worker." She watched and listened carefully to all that went on in the classroom, and then translated for Michelle by tracing on her palm a series of finger and knuckle positions - a process called fingerspelling - which enabled Michelle to "hear" what was being said. That's the part which was most visible to the other students in the program, but in reality Linda did much more.

Ever mindful of Michelle, Linda scheduled her surgery over the school's winter break. "When I told her about my tumor, she hugged me and told me I'd be all right," Linda recalls.

Fortunately, there was no malignancy, and the operation did not affect Linda's vision. "During the entire ordeal we missed only one class," she says with satisfaction.

The two women had met at the Helen Keller National Center for Deaf-Blind Youth and Adults (HKNC) in New York, where Michelle is an assistant teacher. Linda,

who had learned braille as a young mother housebound with three small children, had volunteered to translate books at the Center into braille.

Michelle had been born with a hearing defect, and her hearing diminished over time. As a young girl she was outgoing, with lots of friends; she was an avid athlete and student. But by age 16, she was totally deaf. At 18, she entered Gallaudet University in Washington, D.C., the only university for deaf students in the United States, studying to become a teacher of deaf children. During her senior year, a snowmobile accident left her in a coma. Though she recovered and was able to go home, she suddenly and inexplicably became blind, plunged into a world of darkness. "I felt doomed," Michelle says. "I sat in my room all the time, not knowing if it was day or night. I didn't think I could go on." But she did.

She learned to read and write braille, and new ways to "speak" now that she



could no longer see hand signs. Then she earned the nine credits she still needed to get her B.A. from Gallaudet.

In 1972 she enrolled at HKNC for further training, and later married Bob Smithdas, an assistant director at the Center, who is also deaf and blind. (The story of their special romance appeared in FAMILY CIRCLE on April 15, 1986.)

Michelle became an assistant teacher, but she was determined to become a full-fledged instructor at the Center. To qualify, she needed a master's degree, though very few deaf-blind people in the country have ever reached that level of achievement. She had already tried twice and failed, mostly because she did not have one consistent, dedicated interpreter to help her.

While taking graduate courses at New York University, she became increasingly frustrated and impatient. "I had to sit (in my room), waiting for an interpreter to come and get me," she says. "I felt

completely helpless. For the first time I considered giving up." Then she tried again at another school - Hofstra University on Long Island - but that did not work out either for similar reasons. She needed someone not only to transport her to and from school, but also to transcribe all the written material and textbooks into braille and act as a go-between with her professors. It was a tremendous favor to ask, and Michelle had almost given up on ever finding someone willing to devote the time.

Then she met Linda. She knew from Bob that Linda was an extraordinary person and when she asked for help, Linda immediately agreed. "I thought it sounded like fun," Linda recalls. "Besides, I always like a challenge."

Linda promptly researched schools and found the type of graduate program Michelle was interested in at Teachers College Columbia University. She consulted with Larry Gardner, Ph.D., then

head of the graduate program for Teaching the Blind and Visually Impaired, and he accepted Michelle into the school.

Months before courses began, Linda started laying the groundwork to insure Michelle's success. "I found out which textbooks were assigned and bought two sets - one for myself, so that I'd be familiar with the material, and the other to be transcribed into braille for Michelle," she says.

Drawing on her years of experience in volunteer work, she recruited an army of braillists. At least 3,000 pages of braille were needed per course. In pre-computer days, an experienced braillist could turn out five pages in an hour. "A whole book would be a lot to ask, but I figured most people would be willing to do a chapter," Linda explains.

So she tore Michelle's set of books into chapters and sent them out to volunteers; when she got back the braille translations, she simply tied each book back together



with string and gave them to Michelle.

When classes started, she picked up Michelle at HKNC for the 20-mile trip to the Columbia campus in Manhattan. Driving with one hand in order to leave the other free to grasp Michelle's so they could "talk," Linda wove in and out of rush-hour traffic. They discussed everything from mammography to menopause. "Spending all that time in the car, we talked about things I'd never talked about with other women friends of mine," Linda recalls.

For Michelle, too, that time in the car was special. "It gave me the opportunity to establish a close friendship with another woman - something that had been difficult to do before."

Each week Linda's husband, Ronald, took the subway uptown from his Wall Street office to the campus in order to drive the women home. This left Linda free to sit with Michelle, reviewing and reinforcing the evening's lecture.

In the classroom some small concessions were made. "They adjusted to the way Michelle worked," Linda says. But sometimes the two women were less than attentive, and their giggling did not go unnoticed. "One of the professors told me he could always tell when we weren't paying attention, because he'd notice Michelle laughing," says Linda. "But you simply can't listen for two hours and fingerspell without a break. So I'd describe what the other students were wearing, or speculate about what they were thinking - make little jokes."

Says Michelle, "She got me the information I needed, and she interpreted for me. And," she adds with a wide grin, "we did have fun."

Linda, for her part, was an enthusiastic student too. "I've always loved school and learning," she explains, "and during class discussions, the hard part for me was to hold back. I had to remember I was there for Michelle."

Linda is the type of person who tries to deflect attention from herself to whatever project she's involved in; in fact, her numerous plaques and awards for outstanding community service hang on the INSIDE of the closed door in her living room. So at one point, when it was suggested that she could get HER master's degree as well, Linda refused. "I didn't want to take the focus away from Michelle."

The entire project took Linda about 30 hours a week over the course of five years. "It was time-consuming," she concedes, "but I loved it."

And Michelle is fully appreciative. "I would never have been able to do what I did without her," she says.

It was Michelle's bubbly personality and sense of humor that added a special dimension to their work, Linda says. They both love telling about the time Linda pulled into a handicapped parking space at Columbia and Michelle, by then familiar



with the school's physical layout, hopped out ahead and started toward the building. Linda began to laugh. When she caught up with Michelle, she grabbed her hand and fingerspelled, "I think you'd better at least try to look a little handicapped!"

Indeed, Michelle seldom views herself as handicapped. As part of the course work, Linda once took her to visit a school for physically disabled youngsters, the majority of whom could see and hear. Michelle left, filled with admiration. "She just couldn't believe how handicapped those children were," Linda says. "I was amazed by her reaction. To me, to be both deaf and blind is the most serious handicap of all."

In 1989, Michelle graduated from Columbia Teachers College with a Master's Degree in Education for the Blind and Visually Impaired Learners. Throughout the ceremony Linda was in her usual spot at Michelle's side, with Michelle's hand grasped firmly in hers, the many messages

of congratulations flowing through her fingertips.

Today Michelle, now 42, is an instructor at HKNC. She is also working to develop a simplified version of the braille code, which will be easier to use for those with limited capabilities. Linda, now 60 is expanding the Center's braille library and its corps of volunteers. She also conducts outreach programs in public schools.

Despite their busy schedules, the two friends still manage to visit and go shopping together, but both miss the intimacy afforded by those weekly trips to school. "Helping Michelle was the best thing I ever did," says Linda. "It was the highlight of my life."







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**NAT-CENT NEWS**

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## **EDITORIAL**

### **LIVING AND LEARNING**

by Robert J. Smithdas, LHD, Litt.d., LHD

Life is full of challenges that test our ingenuity and initiative by exposing us to a never-ending parade of problems and unforeseen situations. We are constantly subjected to changes and new developments and relationships with which we have had no previous experience. Certainly this is particularly true for deaf-blind individuals whose unique dual disability creates special problems of adjustment to nearly every aspect of everyday living.

It is human and natural for us to be most concerned with our own frustrations, failures and successes. We often overlook the fact that our lives can directly influence the lives of others - family members, friends, and society as a whole.

In this issue of NAT-CENT NEWS, readers will find several articles which

show how deaf-blindness impacts on family relationships and the attitudes and emotions they experience. Adjusting to the needs and problems of a family member who is deaf-blind or losing both sight and hearing can be demanding and sometimes overwhelming.

How does a sighted-deaf husband relate to his deaf spouse who is losing her sight? How do parents react when they discover that their child is deaf-blind, and how do they plan constructively for the child's future? What are the initial reactions of the family to deaf-blindness, and how do they learn to cope with it? We can learn much from the reactions and responses of families and those who are close to people who are deaf-blind.



## **FIELD NOTES**

### **WHAT'S IN A NAME?**

by Dennis Brady, Assistant Director,  
HKNC

There has been some discussion recently about using the one-word term "deafblind" instead of deaf-blind. I am interested in finding out what readers prefer. Those who support this new idea of a one-word term are emphasizing that the hearing condition and the visual condition must be thought of as a combination. If you only deal with one condition, they say you run the risk of underestimating the needs and problems of the person who is deaf-blind. Here at the Helen Keller National Center (HKNC) we use two phrases - a person who is deaf-blind and a person with deaf-blindness. I have heard other terms used. May I suggest that you write to me or to Bob Smithdas and give us your thoughts on this subject.

## Changes in Field Services Staff

By the time this edition of NAT-CENT NEWS reaches you, three regional representatives will have left the agency and their replacements hired.

Diane Reeves, based in Chicago, Illinois, has resigned and moved to London, England. The new representative for the North Central Region is Dorothy Walt. Dorothy was an HKNC Affiliate at the Alaska Center for Blind and Deaf Adults. She is a board member of the American Association of the Deaf-Blind.

Ron Cyphers has resigned his position in Atlanta, Georgia. Ron was originally responsible for all 8 states in the Southeast Region. Several years ago a second representative was hired to make that job more manageable. Ron had been working with the states of Georgia, Florida, Alabama and Mississippi.

Susan Brooks will be replacing Ron in the Atlanta office. She was the executive director of In-Touch, Inc., formerly an

HKNC affiliate in Minneapolis, MN, and most recently had been working with Dr. Sandra Davenport on her Usher syndrome project. Susan is already known to many of our readers and is a regular at the AADB conventions.

Last but not least, Susan Olson has resigned from her position in Denver, CO, as the Rocky Mountain Region's representative, a position she has held for 12 years. She will be joining the staff of the Virginia Dept. for the Visually Handicapped in Richmond as a Vocational Evaluator/Counselor.

The new representative in our Denver office is Maureen McGowan, better known as "Mo". She had been working with Colorado State Rehabilitation Services as an orientation and mobility instructor. Mo has previously been employed at HKNC as the supervisor of the O&M department and was a member of its National Training Team.

We extend our very best wishes to



Diane, Ron and Sue. They have given many years of service to HKNC and its students. I hope you have the chance personally to welcome Dorothy, Susan and Mo.

Change does not come easy. We will miss our three good friends ... but have gained three new ones.

## **GIVING PEOPLE WHO ARE DEAF-BLIND A HAND**

(Reprinted with permission of Dupont Magazine, Wilmington, DE)

Those who watched the "Miracle Worker" on stage or screen probably recall the electrifying scene when young Helen Keller begins to emerge from the isolation of her deaf-blind world. Jolted by the shock of recognition, she makes the connection between the liquid spilling from a pump and the W-A-T-E-R teacher, Anne Sullivan, fingerspells into her hand.

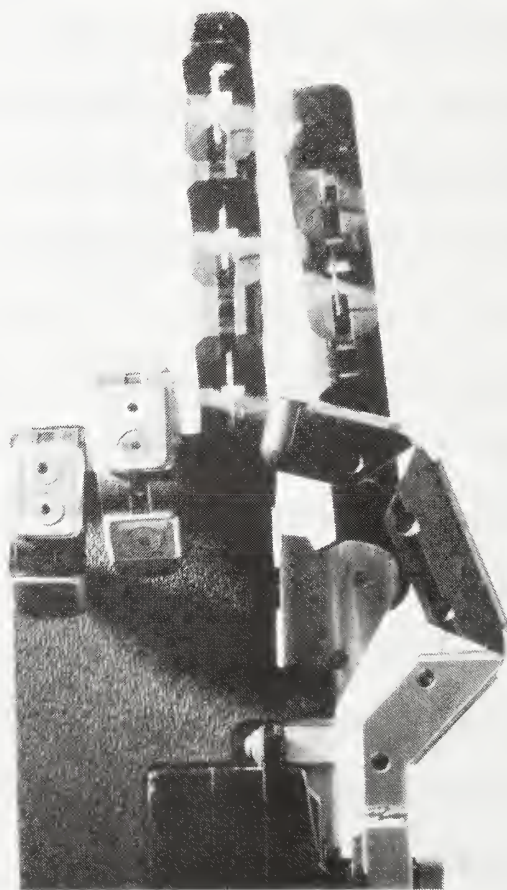
In the fingerspelling or manual alphabet which dates back to 16th century Spain, various finger positions represent individual letters. Deaf Frenchman, Laurent Clerc, brought it to the U.S. when he came to help Thomas Hopkins Gallaudet teach deaf children in Connecticut in 1815. Last year, the Washington D.C. university that bears Gallaudet's name evaluated a 20th century spin on fingerspelling that could one day connect many of the deaf-blind U.S. citizens to modern communications devices, reducing their social and informational isolation.

A computer-controlled fingerspelling hand called RALPH (Robotic Alphabet) lets individuals who are deaf-blind receive print, telephone, computer, and even television messages without a human interpreter to translate them into fingerspelling. Developed by the Rehabilitation Research and Development Center at the Department of Veterans Affairs Medical Center in Palo Alto,

California, RALPH is an electro-mechanical hand mounted in an enclosure housing a motor, computer hardware and custom software.

"RALPH is designed to interface with character scanners, closed caption television and other devices to provide independence and privacy in communication," notes biomedical engineer David L. Jaffe, one of the hand's developers. "It translates keyboard key presses or electronic representations of letters into hand movements that users who are deaf-blind interpret by touch."

As the nation's leading institution of higher education for the deaf and



Ungloved to show black finger segments, RALPH forms the letter "R"



hard of hearing and their teachers, Gallaudet University commissioned the creation of a third-generation hand for evaluation by consumers who are deaf-blind. The Technology Assessment Program (TAP) of the University Research Institute identified nine students who were deaf-blind who participated in the product test.

"Based on our testers' reactions, we see this device as an alternative to braille displays for deaf people who become blind as adults and who haven't mastered braille" reports TAP Director, Judy Harkins. "Many adults who are deaf-blind are amazingly fluent at fingerspelling and can read it as fast as the human hand can make letters - upwards of six letters a second. The best read it without touching the fingers at all, but only the knuckles and bones on the back of the hand."

At about four characters per second, RALPH is slower than the best human fingerspellers. But unlike humans, RALPH's

fingers - composed of segments that are machined of cleaner-processing "Delrin" P performance acetal resin - don't get tired. "Delrin" is the most metal-like unreinforced plastic available.

"We use 'Delrin' because it's easy to machine for making prototypes," Jaffee explains. "We never break any tools working with it. It has a smooth finish, is fairly strong and is not expensive."

RALPH can't exactly mimic human hand movements, but many of its approximations of letters have proved easy to understand by users who are deaf-blind once they get used to its "accent." The movements are consistent, can be edited to conform to personal preferences and operated at different speeds.

RALPH is the fourth generation of fingerspelling hands to grow out of student projects at California's Stanford University in 1985 and 1988. The student work demonstrated that a mechanical hand could be computer-controlled but more

work was required to make it practical. For example, the first design, which used compressed air to operate the pneumatic cylinders that flexed the fingers, was bulky and not exactly portable. The compressed air tank alone weighed 50 pounds, and the entire unit 100 pounds. RALPH, on the other hand weighs less than five pounds including the power supply, and uses DC servo motors and mechanical linkages to operate the fingers.

Many of RALPH's refinements were suggested by testers who are deaf-blind from Gallaudet and elsewhere. For example, testers found that a ten-year-old-child-sized hand provided the optimum in legibility so today's hand is much smaller than the original one. The hand no longer assumes a neutral position between letters because testers found that confusing.

"Human fingerspellers, our testers told us, move smoothly from one letter to the next." Jaffe explains. "So it's not just a



matter of knowing how to make the 26 letters, it's knowing how to move from any one letter to any other letter. Data for those movements were generated by investigators at the A.I. DuPont Institute, a rehabilitative hospital in Wilmington, Delaware. We used the data in our new software to eliminate the neutrals between letters."

Getting RALPH to market is a matter of finding a company interested in producing fingerspelling hands on a commercial scale, Jaffe says. To learn more about giving people a hand, or other products in development to assist people with disabilities, call him at 415-493-5000, ext. 4480.

# **DREAM FOR TOMORROW, BUT LIVE FOR TODAY**

by Paul Odland

(Reprinted from Usher Family Support,  
Summer, 1993)

I was amazed how, within a period of one hour, I learned how precious each moment of each day was. My son, Ryan, now 11 years old, was diagnosed with Usher syndrome type I at age 6. Little did I know then what a blessing it was to get an early diagnosis, even though the actual event was far from spectacular.

Ryan was diagnosed as having profound deafness at the age of 8 months. We were given no known cause. Ironically, I had already started a class in sign language months before, not having even the slightest knowledge of Ryan's deafness.

Prior to Ryan's clinical diagnosis of Usher syndrome, I sensed something else was going on. This was the same way I

had felt prior to the diagnosis of deafness. In March of 1989, Ryan's school teacher noticed that he had dropped his red pen on the white classroom floor. He was using sweeping motions with his hands to locate the pen, which had fallen right in front of him.

Concerned, we went to Ryan's pediatrician, which led to a series of referrals. During that process one ophthalmologist suggested that Ryan had Usher syndrome and mentioned that he would go blind, giving no further information. We were told to wait 3 weeks for an appointment to see a pediatric ophthalmologist at the University of Minnesota. I needed to find out sooner, much sooner.

Through persistence our appointment was moved up. I remember the minutes following the physician's diagnosis; it was overwhelming. I continually reverted back to my thoughts that Ryan was still our beautiful son who had not changed at all.



What had changed was our knowledge of Ryan's identity and the future challenges he would need to confront. Without so much as a blink of an eye, I learned the meaning of the phrase "live for today".

That early diagnosis, aside from the fact that we wish it had never occurred, was a blessing. It gave us time to prepare for Ryan's future loss of vision. It also gave us time to grieve before there was significant loss in his visual fields. I told myself shortly after Ryan's diagnosis of Usher syndrome that I needed to take every opportunity to get him out to experience life. Sometimes we traveled to a lake to enjoy the outdoors. Other times I simply needed to slow down my fast pace of doing things long enough to explain something to him or point out something that might otherwise have passed him by.

Fortunately, Ryan has had the opportunity to attend school with other children who are deaf, hard of hearing, and

a few with both vision and hearing impairments. He also has had mainstreaming opportunities in science, mathematics, and physical education. Ryan participated in a basketball and baseball league several years ago, but due to peripheral vision loss he had difficulty following the ball. We realized that individual sports were perhaps better to pursue. He has participated in karate for 2 years and is at the level of a green belt. He has won one tournament and placed second in another - competing against non-handicapped youth his age. He also loves swimming, boating, fishing, snowmobiling, playing Super Nintendo, watching movies, and having sleepovers with friends from school.

Presently, Ryan is entering sixth grade at Como Elementary. An important reason for his going there is the deaf-blind specialist, Mrs. Paula Knutson. She has helped locate the most optimal seating in the classroom, dealt with lighting

concerns, initiated orientation and mobility evaluations, and started braille instruction, which Ryan enjoys even though he doesn't need to use it now.

Ryan has also had the chance to interact with other people, both young and old, who have Usher syndrome. Good role models are important for self-esteem. One of the most difficult challenges for Ryan as he grows up will be increasing isolation. We, as parents, can help to decrease that isolation by not becoming part of that problem ourselves. Learn sign language. Do not accept lip reading, spoken English, or writing on paper. They are marginally adequate. Your being able to sign is important to your child's self-esteem and feeling of acceptance, especially if your child has Usher syndrome type I. We need to become informed parents and advocates for our children. And through networking with others, our children will hopefully grow up with the positive self-esteem and self-confidence to confront their futures.



I remain somewhat fearful for Ryan's future, but am encouraged that he is building the foundation to successfully confront future challenges. He is my bright, handsome son, but he is also my friend and I am very proud of him. My dreams for Ryan remain strong even though he is challenged by Usher syndrome. Tomorrow's dreams will come soon enough as long as we prepare for tomorrow by living for today.

## **THE WORLD AT THEIR FINGERTIPS**

By Barbara Hausman, Director, Public  
Relations, HKNC

New technology has a tremendous impact on all of us. For people with significant hearing and vision impairments or those who are deaf-blind, technology has miraculously alleviated their sense of isolation and introduced a new sense of independence.

Henry Palmer recently completed his comprehensive rehabilitation training program at the Helen Keller National Center (HKNC). He was born blind and began to lose his hearing at age 25. Now in his early 50's, he is totally deaf and blind. Palmer spent several years packaging items and using a riveting machine. He was bored stiff. "Even my ability to communicate and be effective in the community was lost, just like my hearing," Palmer explained.

At the Center, Palmer learned to use special electronic devices like the TeleBraille II, a portable device with a braille output that can function as a TTY, a face-to-face interpreter, and a computer interface. Then he was able to scan printed material with Os-Ca-R, an optical character recognition scanner which transforms print into a computerized format.

After learning the keyboard and other computer functions, Palmer used a

Navigator to produce high quality braille using various MS-DOS computers. This gave him the ability to read nearly any printed material.



Student/intern, Winnie Tunison, prepares lesson plans using the Navigator with the help of computer instructor, Jim Belanich.

With his training completed, Palmer returned to his home in Gettysburg, Pennsylvania, and went to work at Touch Document Company converting printed materials such as restaurant menus and local electric company bills into braille.

Palmer, a sports fan, now scans and reads articles in the sports section to keep



up with the Philadelphia Eagles - his favorite football team.

Don Achas studied for his high school GED while he was a student at HKNC. He was able to scan and read the constitutions of the United States and of Illinois, his home state. He also took the Stanford Achievement Tests for grade equivalencies in math and reading using his newly learned skill.

While finishing his HKNC training, Bradley Cupit also worked at the Avis Corporation headquarters. He is in his early twenties and is visually impaired and deaf. He is able to use a different method.

Cupit uses a closed circuit TV, which enlarges print up to 40 times, to copy printed material into an IBM computer with VISTA, a text enlarging program which can magnify images by up to 64 times.

Cupit has several aids and devices which make it possible for him to live alone in an apartment. A Vibra-Call wireless paging system transmits basic lifeline

information through a receiver worn on his belt. It vibrates to inform him of the telephone ring, doorbell, or smoke alarm. He uses a large printout TTY to call friends and family.

When Cupit returned to Louisiana to be married his life included a job and a productive lifestyle - all possible because of training and new assistive technology. Though it may be hard to believe, now deaf-blind people can even watch television.

Former HKNC student, Richard Ramm, is partial to "Good Morning, America." Current student, Winnie Tunison keeps up to date with ABC's "Nightly News" and uses a computer to prepare lesson plans and reports for her "teacher-in-training" program. How is this possible?

About 97 percent of network prime-time offerings are close-captioned. Four years ago Dan Hinton, a digital communications engineer with Science Applications International Corporation

(SAIC) in Maryland, developed a "Braille Telecaptioning System" in an effort to help his son who is deaf-blind.

The system was tested at HKNC and improvements were made by Nelson Dew of Dewtronics in Arnold, MD.

Using a TV with a telecaption unit, an IBM-compatible computer, and a TeleBraille, people who live without sight and hearing can watch the Superbowl or a President's address to Congress while they are actually happening - just like everyone else.

Some states (such as Virginia and California) provide TeleBrailles on loan to users. This is significant because TeleBrailles cost about \$6,200. The rest of the telecaptioning system is available from Dewtronics for about \$1,985.

System options include the ability to control the speed of recording of a TV program, to record on floppy discs for reruns at any time, and to output in grade II braille.



"Although these 'high tech' devices can be expensive, in the long run they pay for themselves with increased abilities and productivity for the person who is deaf-blind," said Jim Belanich, HKNC computer specialist.

One of the most positive outcomes of the explosion in technology is that people with severe multiple sensory impairments can hold a wide variety of jobs - teacher, editor, sales person, public relations, secretary, computer analyst, bookkeeper, braille conversation typist, and many more. High school and college bound youths are no longer totally dependent upon volunteer braille transcribers. Opportunities are endless. The world is no longer dark and silent and lonely.

For further information about special aids and devices or about HKNC's computer training program, please contact Jim Belanich at 516-944-8900, extension 251 (voice) and 516-944-8637 (TTY).

## Assistive Technology Products at the Helen Keller National Center

**Braille-N-Print:** A device that allows a Perkin's Braille user to simultaneously produce hard copies of both braille and print. The Braille-N-Print interprets the movements of the Perkin's Braille and converts that information into a standard printer format. The device converts both grades one and two braille into proper English format.

**Braille Telecaption:** A device that converts the signals from a closed caption decoder into the Baudot signal that is used by a TeleBraille. Once converted, the braille reader can access closed captions in a braille format on the TeleBraille.

**Navigator:** A braille display system manufactured by TeleSensory to allow a braille reader to access a computer using refreshable braille. The user can access text-based programs running in an MS-DOS environment. Navigator has a

single line of refreshable braille and 2 sets of directional keys to control the cursor and the display window. Navigator uses a slight variation of braille, using the Nemeth code for numbers and changing a few of the punctuation symbols.

**TeleBraille:** A refreshable braille communication device with 3 operational modes: face-to-face, telephone, and Navigator. In the face-to-face mode TeleBraille can be used as a print-braille interpreter with the braille reader reading information from a braille display and a sighted user reading from a print display. In the telephone mode TeleBraille acts as a TTY with a refreshable braille output. In Navigator mode, TeleBraille acts as a 20-cell Navigator.

**VersaPoint:** A braille embosser (printer) which produces a hard copy of braille. VersaPoint prints in various braille formats (grade one, grade two, foreign languages) at 40 characters per second and comes with software to type out pictures or



graphics in a braille image.

**Vista:** A text-enlarging system by TeleSensory. With Vista all commands are controlled through a special mouse. The system magnifies the screen image from 2 to 16 times the original size. Vista can magnify all or part of the screen.

**Zoom-Text:** A text-enlarging system by Ai Squared. The system magnifies the screen image from 2 to 16 times the original size. The system is controlled by use of several command keys designated by the program. Zoom-Text can magnify all or part of the screen.

## **SEATTLE RESTAURANT WINES AND DINES AND SIGNS**

By Roxanne Patel

(Reprinted with permission from the  
Seattle TIMES, Seattle, WA)

Jennifer Bergeson greets her customers  
with a smile and passes them lunch

menus. She introduces herself, recommends the gumbo and then waits, pen in hand, to take their orders.

She is friendly and calm in the midst of the bustling lunchtime crowd, and nothing seems unusual about her service or about the Ragin' Cajun restaurant, which is located outside the Pike's Place Market in Seattle, WA.

Nothing, that is, until Bergeson's assistant, Sean McIntyre, begins motioning with his hands, translating the customers' orders for gumbo and red beans into signs Bergeson can understand. Suddenly, it becomes clear why the volunteer from Seattle Central Community College is standing next to the waitress.

Jennifer Bergeson, head waitress and manager trainee, is deaf.

"I didn't realize she was deaf until the interpreter started using signs," said Robin Willborn, a lunch-time customer. "Then I talked to him and he talked to her and it worked really well."

Bergeson, who has been deaf since birth, is one of six workers with disabilities at Ragin' Cajun. That group also includes the owner and chef, Danny Delcambre, who is deaf and legally blind. There is a deaf and blind weekend dishwasher, Robert Terrazas, two other deaf waitresses, Sandra Gordon and Ali Hamar, and Sam Fournier, a 55-year-old developmentally disabled man, also a dishwasher.

Bergeson can read lips and speaks clearly, but Delcambre and the other waitresses rely solely on interpreters like McIntyre and Tahoma Piekerk - volunteers from Seattle Central Community College - or on other employees, all of whom must know sign language to work there.

"We want to make the restaurant unique," Bergeson said. "We want to show the world that people who are deaf can do anything to set up a business and make it successful."

Delcambre, 34, is a Louisiana native



who has been deaf since birth and has severe tunnel vision, which means he can see only what is directly in front of him. He opened Ragin' Cajun in April 1993, after realizing no other restaurant would hire him because of his disabilities.

"They all wanted me to start out as a dishwasher, and I knew if I really wanted to work as a chef I would have to do my own restaurant," Delcambre said through his wife and interpreter, Holly Delcambre.

Delcambre studied culinary arts at Seattle Central Community College for a year and then interned for New Orleans' chef, Paul Prudhomme, for a few months before coming back to Seattle to strike out on his own. Delcambre said that a counselor from the Small Business Association helped him through the tough process of getting a loan and setting up the business.

Delcambre's restaurant is small and diner-esque, with booths along the wall, stools at the counter and, on nice days, a

couple of tables outside. The shaded windows protect Delcambre's eyes, and the kitchen is perfectly ordered so he can easily grab the utensils and spices he needs to cook. He works with his back to customers, but turns around to answer questions about his past, the food and the restaurant.

Ragin' Cajun gathers a good crowd at lunchtime when Bergeson and a waiter, Chris Burnett, both work. Burnett can hear, but uses sign language to talk to Bergeson and Delcambre. McIntyre watches the waitress in case she needs him. They all survey the room from the counter, on which there is a jar for contributions to the Seattle deaf and blind community.

Most customers don't notice anything different about the restaurant at first. Sometimes, Bergeson tells them right away that she is deaf and introduces her translator so they know what is going on. Other times, she lets them figure it out for

themselves. Either way, patrons are impressed.

"They look up with a wide reaction when I tell them," Bergeson said. "Then they really seem to like it. They want to learn to say 'thank you' and 'delicious' in sign language."

Delcambre hired Bergeson to wash dishes through SCCC's Program for the Deaf and then brought her out into the restaurant to help deaf customers who came in droves to support the new restaurant, Holly Delcambre said. Soon, Bergeson became a full-time waitress, and now she is training to be a manager.

Danny Delcambre said he plans to hire more deaf employees because they memorize the menu faster, work harder and make better tips. He added that their presence "puts everyone at the restaurant on an equal footing."

The Delcambres said they want to keep the restaurant small so Danny Delcambre can manage it, adding that they didn't



open Ragin' Cajun to make a lot of money, but to give the chef a place to use his skills.

"I'm not surprised by how well this worked out," Delcambre said. "I know deaf people can succeed. It's other people who are surprised."

## **DEVICES HELP DEAF-BLIND MAN COMMUNICATE**

By Amy Maginnis

(Reprinted with permission from the  
DAILY REPUBLIC, Fairfield, CA)

The excitement on David Bess Jr.'s face was obvious. He smiled and moved about excitedly as he set up his TeleBraille I - he was ready to talk.

The TeleBraille is a device that enables face-to-face communication between a person who is deaf-blind and a sighted person, or telephone communication between a person who is deaf-blind and

a n o t h e r   p e r s o n   u s i n g   a  
Telecommunications Device for the Deaf  
(TTY).

Bess, 32, was born deaf and lost his sight when he was 5. He's never viewed his differences as disabilities, just challenges. Bess was one of the first deaf-blind people to learn how to use TeleBraille more than a decade ago.

Just a few weeks ago he got to try out several new products developed to help blind and visually-impaired people achieve greater independence by TeleSensory, based in Mountain View, CA, the manufacturer of the TeleBraille.

Now, all Bess can talk about is the BrailleMate, a hand-held, one pound computer - about one-fourth the size of his current computer. "It's so very small," he typed out on the braille unit in answer to a question on why he liked the BrailleMate. The BrailleMate organizes, stores and retrieves information.

Patrick Duffey, a vocational

rehabilitation work activity program coordinator with Solano Work Services (SWS), would like to see Bess get a TeleBraille III, an updated version of his current model. "It's just a superior device," Duffey said. "It's like a little computer and has quite a bit of memory. David's abilities have advanced beyond his current computer. Equipment such as the TeleBraille III would really give him an edge in the work world. Incorporating this new gear, I think he would be great doing data entry," Duffey said.

"I'm excited," said Bess' mother, Janie Bess. "I think this new equipment will open a lot of doors for David. His language skills are much more advanced than other deaf and blind people." Janie Bess would like her son to work with computers because he enjoys them.

But the fun is only beginning for David Bess. In February, he got the opportunity to try out more computer equipment for people who are deaf-blind when



representatives from a second company, HumanWare, stopped by SWS.



While a student at HKNC, David Bess enjoyed his classes with Phine Haugh, supervisor of the Independent Living Department.

SWS provides vocational training and job placement services to Solano County adults with s e v e r e developmental, physical and e m o t i o n a l disabilities.

B e s s h a s worked in the SWS workshop almost one year. There he does most of his communication by fingerspelling,

which he has taught fellow employees and the staff. Wednesday, he was named the SWS Employee of the Year.

Bess is a unique individual, said Lu Brunet, SWS executive director. "I've

been working in the field 20 years and this is the first time I've seen a deaf-blind person do so much. He's incredible," she said.

"I'm always amazed at the things he does," said Janie Bess of her son. "He makes his own lunch and slices his own cheese. Sometimes we forget he can't see."

Bess attended the Helen Keller National Center in New York for two years and lived in an apartment 18 months in Berkeley, CA, while attending a school for the blind.

As a teen, he was featured in Jet Magazine for translating some of Johnny Mathis' music into braille for Mathis' musicians. He also taught his two younger siblings how to swim and enjoys horseback riding and skiing.

## **A SILENT BUT LOVING WORLD**

by Beverly Beyette

(Reprinted with permission from the Los Angeles TIMES, Los Angeles, CA)

From a simple pulpit flanked with red poinsettias, Jim Hansen is talking about Christ's birthday - about forgiveness, caring and sharing. "We need to be happy with people who are happy," he tells his flock, "and we also need to be sad with people who are sad; to help people carry the burden of sadness."

As his fingers spell out his words in sign language, Hansen stumbles on "sad." From the back, where she is interpreting for a man who is deaf and blind, Muriel Hersom coaches, "Keep your hands open, Jim."

Each Sunday, parishioners who are deaf or deaf-blind come to Grace Bible Church in Highland Park, CA, to worship. Most live in the adjacent apartment complex where, for 18 years, missionary



Muriel Hersom has been housemother. "The Lord has never failed us yet," says Hersom. She needed a van. He provided. A little extra for Christmas treats? Again, He provided.

Her work is supported through donations sent to the mother mission in Lawrenceville, GA, earmarked for Muriel or her Commission on Compassion for the Deaf-Blind of L.A. She is one of 300 missionaries worldwide serving the ministry.

Hersom, 58, lives and works in a largely silent world, but she has no time to be lonely. Though most of the residents can neither see nor hear, they sense when she's not around. And she'd better have a good excuse. By the touch of her hand, they'll decide whether she's mad at them. And, Hersom says, "If you hurt their feelings, they grieve all day."

Some are human castoffs. They may have been abused by relatives or spent years in mental hospitals. As one

apartment resident said, until someone reaches out to you "being deaf-blind is like being in a casket."

As a child in Maine, Hersom spent a lot of time with grandparents who were deaf and she told herself, "This is going to be the end of my being around the deaf." But at the Moody Bible Institute in Chicago, she learned American Sign Language and later was on a team sent to a home for the deaf to teach Sunday School and offer religious services. There, for the first time, she met a deaf-blind man. They quickly bonded. But, she says, spending her life working with people who are deaf-blind was the furthest thing from her mind.

When she was 23, she went to Jamaica to work with deaf children and, nine months later, she moved to Puerto Rico to teach deaf children Bible studies and everyday survival skills.

Later, she returned to Maine to be treated for a back injury she'd suffered several years earlier in a car accident.

There, a friend introduced her to a woman who was deaf-blind. The woman told her that she had coped well with being deaf, but when she also became blind, "It was like poison." She asked Hersom, "Don't you believe the Lord loves the deaf-blind, too?"

For Hersom, it was the moment of truth. Though she fought it, she soon understood that this was to be her calling. She recalls that one day, as she was reading Scripture, "It just seemed so clear. Then I relaxed and said, 'OK, Lord, it's your challenge. I'll follow.'"

In 1963, she moved to California for health reasons and, through church connections, made contact with people who were deaf-blind. Soon, she was going from home to home to see them, driving a 1942 Dodge she'd bought for \$50.

To get them out of their rundown apartments and away from unscrupulous landlords, Hersom started moving them



into her apartment complex in Silver Lake. She began dreaming of a place where they could live independently but together and, as she always says, "The Lord provided."

In the fall of 1976 - five years after Hersom affiliated with what is now Biblical Ministries Worldwide, the Georgia-based mother mission - the group moved into the Highland Park compound. There, a staff of nine help her run things.

Three years ago, Pastor Hansen, 40, and his wife, Joan, and their four young children moved in. Right off, Hansen says, "I made a pact with the congregation. I'd teach them the word of God. They'd teach me sign language."

For his part, it's still a bit of a struggle. While preaching, he has to work his way through words like "disciples." In his church, the deaf interpret for those who can't see or hear, spelling out the words by drawing letters on their palms. In the front row, Roberta Distad, who is deaf, interprets with her fingers for those who

are partially sighted on either side of her.

In sign language, Judy King - in a green skirt, red stockings and red shoes - leads the other deaf congregants in "Oh Come, All Ye Faithful." Those who can speak sing along. Some remember the melody from when they could hear. Others must imagine it.

After services on this day, there will be a holiday meal in the dining hall. The tables are laid in red and green and there is a tree and swags of greenery. Later, the residents who are blind will feel the decorations and, Hersom promises, "They'll see more than sighted people do."

This year, there is also the specter of death. Several residents are gravely ill. In his sermons, Hansen never avoids the subject. "They've all suffered so much," he says. "But if you're a believer and you're deaf or deaf-blind, in eternity you're going to hear. You're going to see. Death is a time for rejoicing."

## **STEEL TOWN PRIDE**

By Cynthia Ingraham, East Central  
Regional Representative, HKNC

Anyone who has ever visited the Greater Pittsburgh, Pennsylvania, area in the fall realizes that it is a spectacular place filled with the colors of autumn saluting the city. On September 14, 1994, the gold, amber and magenta hues danced with delight before a group of people who could only recall what beauty this once exhibited, for now they were without sight.

In the midst of nature's tradition for Pittsburgh, another tradition began. The Western Pennsylvania Association of the Deaf-Blind (WPADB) held its first awards banquet to honor the consumers, professionals and agencies that have displayed a tireless commitment to people who are deaf-blind. The group set up three different awards categories and one special award for the event.



The Robert J. Smithdas Award was granted "to the person who is deaf-blind for their service in promoting awareness of deaf-blindness." The recipient of this year's award was former HKNC student, Lorraine Musial. Ms. Musial expressed her surprise and happiness at receiving the award and thanked everyone with a sweeping "I love you."



Lorraine Musial receives the Robert J. Smithdas Award from its namesake while president of WPADB, Richard McGann and others look on.

The second award, the Susan M. Lynch Memorial Award, was provided "to the professional who has shown leadership and advocacy in the field of deaf-

blindness." The recipient of this award was Cheryl Kennedy of the TRACES Project, based at the University of Pittsburgh.

The WPADB-SSP Award was given "to a person who has given support in many different ways to the members of the deaf-blind community." The award, ironically, went to a person who, although she has never attended an AADB Convention herself, has helped since the inception of WPADB to send consumers and volunteers across the country to numerous conventions. This year the SSP Award went to Rita Visco, who has worked really hard to sell spaghetti dinners to raise money for those people from the Pittsburgh area who want to attend the convention.

Lastly, the special award set up for the evening was to commend the Pittsburgh Blind Association (PBA) for its commitment to the population and for sponsoring this first banquet. Robin Schmidlin from PBA

accepted the award for the agency.

So now that WPADB has established itself as a very influential group of consumers and professionals, it is only fitting that they also establish an annual event to highlight the success that its membership and those who work closely with them have achieved. The next time you are in the Steel City in the fall, remember that Mother Nature is continuing with yet another tradition that displays the spectacular beauty of the town, the commitment to helping your fellow man and to making the lives of others more colorful.

Congratulations to WPADB and its membership for a job well done. We ask that you keep up the good work so that others, consumers and professionals alike, can partake in the multiple splendors of fall.

Following is a brief history of the WPADB:

In March, 1985, the first meeting was



held at the Catholic Office for the Deaf Center in South Side to discuss the plans for 1985 AADB Convention in New Jersey. Nineteen people from Western Pennsylvania participated in a deaf-blind workshop and training and attended the convention in June, 1985.

With encouragement and enthusiasm by those people attending the convention, Western Pennsylvania Association of Deaf-Blind was formed in October, 1985. In November, the first election was held and the following officers were elected: President, Richard McGann; Vice President, Stu Turk; Secretary, Zetta Murphy; Treasurer, Mike Sullivan.

Since 1986, the Association has advertised and presented important workshops and testimonies to educate the public about the deaf-blind community in the Commonwealth and nationwide.

A workshop was presented in January, 1986, at the National Catholic Office for the Deaf Convention in Florida. The

Association hosted the AADB Convention at California State College in June, 1987, with 420 attendees and 72 Pittsburgh participants.

The Board of Port Authority Transit (PAT) was lobbied and given testimony in favor of public transportation for people who are deaf-blind. ACCESS began providing transportation to deaf-blind people in July, 1987.

In January, 1988, the Community College of Allegheny County (CCAC) provided the first credited course on deaf-blindness through the Interpreter Training Program (ITP). Four students took the course.

Pennsylvania Society for the Advancement of the Deaf (PSAD) provided the interpreters for people who are deaf-blind to attend the Leadership Training Program held in May, 1988. A resolution to include deaf-blind people in PSAD activities was submitted and approved. An article about deaf-blindness was featured

in the PSAD newsletter.

In August, 1990, WPADB provided input on videotape for USAir on the needs of people who are deaf-blind. In September, 1990, a braille workshop was offered with 25 people attending.

Since 1990, the number of WPADB participants attending the annual conventions for the deaf-blind in various cities has grown to about 40 and will hopefully continue to grow.

## **HUSBAND ADJUSTS TO WIFE'S CHANGING NEEDS**

by David Williams (English Translation by  
Susan Brooks. Reprinted from Usher  
Family Support, Summer, 1993)

Kimberly, my wife, and I were attending the same church in 1978. The pastor asked the congregation to pray for Kimberly's eyes. I knew her only slightly from before when we both had attended



St. Paul Technical College.

Later some of my friends and I were headed to Indianapolis for a weekend wedding. Kimberly joined us. She had told her friend she needed guiding at night, but when we stopped along the way at a friend's apartment her need for a guide was forgotten. As I looked over my shoulder I saw she had been left stranded in the parking lot. I walked over where she was standing quietly; she looked so helpless. When I signed to ask if she needed any help she did not respond. As she struggled to grasp my arm in the dark, I understood she needed guiding to the apartment building. When we reached the brightly lit building Kimberly became very independent. I asked her if she had vision problems. She was embarrassed by the question, but explained she could not see at night. I had a lot of respect for her independent spirit and I liked her.

As I came to know her better, I guided her more and more at night and brought a

flashlight for communicating at night in the car. Most of the time Kimberly turns on the inside car light to communicate. I used to get embarrassed because everyone could see us as we talked with our hands flashing in the lit car. It seemed everyone in passing cars would look our way and stare. I am used to it now and it is easy to ignore people looking at us. However, one time we were stopped by a policeman. He asked us to turn the light off. We were really surprised since we had been using the light for many years. That was the only time we have ever been stopped.

Before we were married Kimberly was still driving. I recall once when my right leg was in a cast she drove to my apartment. It was so nice having her around to help with cooking, cleaning and to have long chats. She does not drive any more since her vision has become worse, so I do all of the driving. Sometimes she rides the public bus or Metro Mobility. She misses not being able to be spontaneous and go out

shopping or visiting friends on a whim. The bus is limited by their schedule and Metro Mobility requires a phone call 24 hours in advance. They often are booked and cannot accommodate her needs. We live near bus service which is not too far from the city so mobility is not limited and Kimberly can remain independent.

There have been changes since our marriage. Kimberly no longer drives, she uses a magnifying lens to read the newspaper, and depends on her white cane to travel safely. I enjoy walking with her when she has the cane in crowds. Everyone respects the cane and gets out of the way, and I walk behind her. When I am guiding her she still uses the cane to feel the curbs and steps. Some of her friends have been hit by cars when crossing the street without their canes. Kimberly is frightened to cross heavy traffic without assistance, and I would rather have her be safe than sorry. Today it seems like there are a lot of crazy



drivers. I know she wants to do things by herself, but I realize she needs me more than she did when we were first married.

I have noticed another change. Kimberly used to be very fussy about cleaning up the hairballs our cats vomit on the floor, but now she has difficulty seeing them. Sometimes I help her by pointing out the hairballs on the carpet because I get tired of picking them up all the time.

Kimberly takes care of her health. She drinks carrot juice every day. She hopes this will keep her vision strong. She does not want to become blind. I also want her to see clearly so she can enjoy things like I do. Sometimes I wonder and wish I could donate one of my eyes so Kimberly could have one eye to see clearly with a wide range of vision; it would be better than the eyes she has.

Sometimes I have asked Kimberly silly questions about her ability to do things. One night she took out her doorkey, slipped it into the keyhole and unlocked

the door. I asked her how she could see the small keyhole in the dark. I remember watching her in amazement, but now I just take those things for granted. I know she has the ability to do many things for herself.

## **THE PERKINS OUTREACH PROGRAM**

(Reprinted from THE LANTERN, Perkins School for the Blind, Fall 1993)

Geraldine smiles brightly as she signs with quick gestures and animated facial expressions. Her warm smile and bright eyes are indicative of her effervescent personality. Like all teenagers, Geraldine DiCarlo lives a very busy life, balancing her time among school, homework, and social activities.



Despite her schedule, Geraldine, who has been deaf all of her life and has limited vision, is an active participant in Perkins

Outreach Services. For almost ten years, she has been coming to Perkins for low vision evaluations and consultation from the New England Center for Deaf-Blind Services. Today, the Outreach Program represents more to Geraldine. It is an extracurricular activity "where she can learn valuable skills and socialize with her peers at the same time," says Outreach Supervisor, Beth Caruso.

A senior this year at The Learning Center For Deaf Children in Framingham, MA, Geraldine must make a decision whether to work or go to college when she graduates next Spring. Although she is going to apply to colleges this winter, the job market is something she is interested in learning more about. During the summer, Geraldine attended a five-week Outreach Program at Perkins entitled, "A Sampling of the World of Work." Geraldine signs, "The best part of the program was having a real job for the first time, and a salary." This program gave her the opportunity to



earn and save money for the future.

While in the program at Perkins. Geraldine worked in Watertown at The Vision Foundation and in Jamaica Plain at the Brookside Community Health Center. For four days each week she learned office tasks such as filing and copying. Initially a job coach who knew sign language would accompany Geraldine to her work site to interpret and help her get settled. Once she became more independent, Geraldine would go on her own and use a pad and pencil to communicate with her co-workers.

Each day the program continued into the evening hours when teenagers attended classes to learn about the job application process. In these sessions, they worked on creating resumes and business letters and learning interviewing skills. Other areas of discussion covered topics such as communication in the workplace and problem solving skills.

During the final week of the program,

students were required to schedule an informational interview to learn more about the profession that interested them the most and to practice the skills they had learned. Because she might be interested in the field of counseling people who are deaf, Geraldine talked with a counselor at a mental health clinic in Boston which has many deaf patients. However, Geraldine's favorite class in school is computer science, and this may be another area of interest for her to explore in the future.

Throughout the five-week program, students were asked to keep a journal of their experiences, and Geraldine has continued to keep her journal at home. She has also kept in touch with several of the other teenagers who attended the program. As well as being a career resource for Geraldine, Outreach Services at Perkins also provided an opportunity to make new friends.

This fall, Geraldine also participated in a Perkins Teen Weekend trip to Cape Cod

with 12 other students from New England. The group enjoyed a ferry ride to Martha's Vineyard, where they went for the day to hike, shop and see the sights. They spent two nights together on the Cape where they cooked their own meals and played musical instruments around a bonfire. On Sunday, they visited Cranberry World at the Ocean Spray Plant, where their guide was a former Outreach participant.

Perkins Outreach Services has given Geraldine an opportunity to explore her independence. The confidence and skills she has gained will ease her transition as she makes a decision between college and the world of work. Like all teenagers who are ready to become more independent, Geraldine assures her mother, "I am eighteen years old, I am ready."



# **PERSISTENCE PAYS OFF FOR FATHER, SON**

by Gary Karow

English Translation by Susan Brooks  
(Reprinted from Usher Family Support,  
Summer 1993)

The physician reported Scott was a healthy baby, however, the first 9 years of his life were spent in and out of doctors' offices. The diagnosis of a heart murmur caused referrals to the Mayo Clinic, but the specialists said something else was "wrong". Our healthy baby was "floppy", not responding correctly, unable to support himself. The maze of medical language and puzzled faces without the assistance of a sign language interpreter left us dazed.

I was prepared for a deaf child and thought that would be no problem as I am deaf. The hearing tests were inconclusive; he was too young to respond. We were told, "Wait until he is one year old." Finally, at age one we found he was "not

responding correctly" to the hearing tests. His eyes were fine. His heart murmur had mysteriously disappeared with no explanation given.

During the preschool period of Scott's life his mother and I noticed he needed to be close to objects he was interacting with. He would lean into his food, sit right in front of the television set, and draw books almost to the tip of his nose. Our family doctor referred us back to the Mayo Clinic for vision field tests. They were looking for Usher syndrome, but it was ruled out. Looking back it seems the doctors were unwilling to identify his condition because they were unsure.

Scott was still "floppy" at age 3, but he did fine in preschool. Around age 9 the Minnesota State Academy for the Deaf in conjunction with the Minnesota Department of Public Health had a vision screening for all deaf students. We received a letter in the mail after the screening that referred us to the University

of Minnesota for further testing.

I will never forget the terror of that testing. Scott and I were in a dark room. They put contact lenses on Scott's eyes and continued the testing for 4 or 5 hours. Scott was in pain and he cried constantly, clutching me, refusing to break his grip. I was scared too and his fear affected me. Again there was no interpreter. We were left alone in the dark with only our fear to console us. Occasionally the technician would come in and write a note. My mother accompanied us and she was in and out of the room.

A few weeks later we got a one page letter in the mail with a copy sent to the school. Scott had Usher syndrome. My mother focused on "blindness" and became upset and cried. Scott did not fully understand, he kept signing, "Why must I ... ? "Why me?".

I tried to focus on the day to day routine and to "take it easy." Scott got prescription glasses, although in school he



refused to wear them. He sat in front. The teachers insisted his glasses would help the Usher syndrome. I had to educate them about Usher syndrome; I knew glasses would not affect his peripheral vision.

During the Individual Education Plan (IEP) meeting we requested a large print dictionary. The teachers said, "Well, if glasses don't help, how can a large print dictionary?" I bought Scott's dictionary myself. The IEP never satisfied Scott's needs; it never provided anything special. Once, the Minneapolis Society for the Blind provided a low vision screening. They said Scott did not need any special devices; he could get along fine without them. Finally in his senior year, the Division of Vocational Rehabilitation (DVR) for the deaf became involved in planning for Scott's transition after high school. When they discovered his vision impairment they quickly referred him to State Services for the Blind (SSB) for services. We had to go

get a new eye test and a new eye doctor, who told us Scott could see normally. SSB tried to give Scott's case back to DVR, who refused to accept it. The SSB counselor told us if he opened a case for Scott, their office would have to inform the Department of Motor Vehicles and Scott would lose his driver's license. Scott was upset because he knew he could see to drive and his driver's record was good.

Scott is now at the Faribault Technical School. He had a counselor who recommended he take accounting. This major was not a good match for Scott and he experienced frustration with understanding the interpreter. He dropped out of school. He has re-enrolled full time this fall, changed interpreters, and changed majors to computers and general office work. He hopes to graduate next spring.

For many years we were frustrated with the educational, medical and agency services that did not provide enough information and support to Scott and our

family. My advice for families is, if you know your child has a vision impairment, keep bugging to get their needs met. If necessary, seek legal counsel to enforce your child's rights. The doctors were right about one thing; Scott is still a healthy child.

## **CONQUERING CHALLENGES AND BUILDING CHOICES THAT LEAD TO INDEPENDENCE**

By Christopher A. Harmon

Introduction by Julie Devich, staff writer

(Reprinted with permission from  
SIGNALS, FIND, Inc., Minneapolis, MN)

The following is an excerpt from a speech by Christopher Harmon, President of the Board of Directors of FIND, Inc. Harmon's speech was presented at a PACER Center workshop in October. Portions of the speech were also presented at this year's annual Minnesota Deaf-Blind



Association Thanksgiving Banquet. Harmon, 23, is a freelance writer and public speaker. Here, he eloquently describes what may be regarded as negative experiences and how he transformed them into positive life lessons.



I like to think of my life as being comparable to a video game. In many of today's electronic games, you must navigate a series of obstacles and mazes, and earn as many points as possible, with the goal being to survive to the end of the game. The more experience you have, the better you play.

You have two options: You can proceed along the obvious path or you can choose to confront the challenges. If you choose the more challenging path, you must seek out secret doors, hidden treasures, and fight an occasional monster. I chose the more difficult path. Seeking

out the hidden doors often led me to agencies and/or services I didn't know existed.

When I was born in Indiana, June of 1970, I was proclaimed a normal child and given a clean bill of health. The first signs that something was not right - not responding when called and falling often - began at five. It truly may have begun through a contraction of spinal meningitis at age one-and-a-half that was undiagnosed until it ran its course, even though I seemed to completely recover. Things continued to worsen until my parents brought me to a hospital in Philadelphia. There, doctors discovered that I had scar tissue on my brain stem and diagnosed me with a rare condition known as Spinal Cerebellum Degeneration (SCD).

SCD is a non-transmittible, non-inheritable neurological disorder that slowly chokes off the communication link between the brain and the body's muscles.

The person will experience gradual loss of sight, hearing and muscle control. As of this date, no known cure exists. From the medical world's standpoint, I am no longer a person. I am now a deaf-blind quadriplegic. I have become my disability.

When I was in seventh grade, my family moved to Minnesota. I was lost in a sea of unfamiliar people who had never had contact with a disabled person. This was hard on me. It took me a long time to adjust to being alone. My self-esteem began to slowly erode away.

My special education case manager, Tom Riniker, eventually realized what was happening to me. Up to this point, I had been only a mediocre student. Tom suggested that I engage in a "private little war." He told me that academics was the great leveling field and on the field I could wage "war." I could quietly compete with other students. I decided that he was right and settled down to map out my battle strategy.



At about this same time, I found another way to compete with other people through sports. During my junior and senior high years, I was a member of a team that played adaptive floor hockey and soccer. That was quite an experience! I couldn't see that little, red plastic puck very well, even when it was right at my toes. I had to learn how to analyze the movement of the destination. I also had to watch my teammates to figure out what play the captain was setting up. There's nothing more intimidating than having a whole herd of buffalo stampeding your way - and knowing the puck is probably inches away from you - but not knowing where. It takes a lot of guts.

In relation to this, have you ever noticed how churches tend to be located on street corners? I think it is a recruiting technique aimed at the deaf-blind because intersections are where many of them find religion. It is very common for drivers to turn corners during red lights, and how

often have you seen one of those aluminum monsters roar right past a stop sign doing 55 on a 35-mile-per-hour road? Believe me, it can be very hard taking that leap of faith. I lucked out here a little. My experiences on the team taught me how to interpret traffic patterns to determine when and where to go. But it is still daunting for me.

Time passed and I added thickness to my wall as an oyster might add to its shell. By my senior year, I was dangerously close to being a misanthrope, which means I almost hated all mankind. Then something happened, something I had long ago taken for granted as being impossible. A path magically appeared through my wall, linking me to the outside world. It was a narrow path, but, nevertheless, it was there.

The path was created by a few simple words spoken by a few ordinary human beings. This took place at the 1987 Thomas Jefferson High School

Homecoming Coronation. Before then, I had known for some time that I was to take part in the event as one of the two senior ambassadors. I was somewhat surprised at the time, but I chalked it up to patronage.

What I had not known was what the students had in store for me. They dedicated a song to me entitled "Love in Any Language," which they sang in voice - and in sign language, a language I depend on in my daily life. I was too stunned then to show any reaction. After all, how would you feel if you suddenly found an opening in your supposedly impenetrable wall? An opening created not by the savage forces of atomic power, but by a song that gave a simple message, yet packed with enough punch to change the course of your life? But as I later wrote in our school newspaper, "I am not ashamed to say, that night, I wet my bed - with tears."

Star Trek's founder, Gene Rodenberry,



beautifully expressed what I learned during my experiences at Homecoming: "To be different is not necessarily to be ugly; to have a different idea is not necessarily to be wrong. The worst possible thing that can happen to humanity is for all of us to begin to look and talk and act and think alike."

Ever since then, I have been pecking away at my shell and have been slowly, but surely, expanding my social circle. Through the crack in my shell I saw others enjoying the diverse activities in life. Then it dawned on me - I was not the only person with a shell! For whatever reason many of us have allowed shells or walls to grow around us; we all have to work to free ourselves of the shells of isolation that have encased us for so long.

No one can tell you how to play your game, but I strongly encourage you to play it to the fullest extent. Yes, that will mean a lot of extra work, but the rewards you reap from a newly-conquered challenge

will bring you that much closer to a life of independent living. The decision is yours.

## **HERE AND THERE**

A HANDBOOK OF BRAILLE CONTRACTIONS, compiled by Harry Schuman, is available from the American Action Fund for Blind Children and Adults, 18440 Oxnard Street, Tarzana, CA 91356. It is a sensibly organized, easy-to-use list of all grade two braille contractions in a convenient booklet. The booklet is free, and orders should be sent to the above address.

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